Challenge

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The Challenging Behaviour Foundation

Health & Support Post Covid

To read online, please see: http://bit.ly/CBFNewsletters

There is almost daily coverage in the media about the challenges faced by our national health service, coping with the backlog from the pandemic. In this issue we consider what that means for children and adults with learning disabilities and their families. We already knew, and there is lots of evidence, that this group of children and adults face additional challenges in getting their health needs met from health needs not being identified in the first place, to the challenges of attending appointments where no reasonable adjustments have been made.

We know that it is possible to meet people's health needs if there is flexibility and if health professionals value and listen to the individual and those who know them well. In this newsletter we hear from a family carer who has advocated strongly for her daughter to get access to treatment she needs, and also about one Health Trust who have prioritised the health needs of individuals with learning disabilities because of the known health inequalities they face.

Early identification of health needs, including through screening for sight, hearing and dental problems, can lead to early treatment and help, and to avoid more serious issues later on. The link between unmet health needs and the development of behaviour that is described as challenging is also well established. Early input makes sense both from the individuals perspective for their quality of life, as well as financial sense for "the system", avoiding costly later support which is often at crisis point.

The CBF has resources available that set out your rights to healthcare and reasonable adjustments as well as practical tips to get access to good healthcare – we hope you find them useful.

Vivien Cooper
Family carer and
CEO of the CBF

Resources in this issue

All the resources featured in this edition of our newsletter (and many others) are available on our website. Visit the website for news, opinion, information, resources, opportunities, and support!

Remember that you can receive our newsletters directly in your inbox if you subscribe here. We can post copies of resources to families call us on 01634838739

Contents

What is the CBF? We are a charity supporting children, young people and adults with severe learning disabilities whose behaviour challenges, and their families.

Reasonable Adjustments or Unreasonable Treatment?

Accessing healthcare and regular health checks help keep everyone healthy, but we know often people with a learning disability experience additional barriers. With the delays due to the covid pandemic still impacting on waiting times and available services, we ask what can be done to support better access to healthcare for people with severe learning disabilities. Browyn shares her and her daughter Rachel's experience of accessing healthcare and overcoming poor support when requesting treatment at her local hospital.

Boxing Gloves

When you give birth to a special needs child you need a good pair of boxing gloves!

When my daughter, Rachel, was 10 days old I had to fight to get a second opinion. She is now 31, with profound learning disability, and I have never stopped fighting!

She lives in a wonderful care home in Taunton and 9 months ago started walking awkwardly. X-rays showed she had a problem hip and she was referred to Bristol Royal Infirmary to a consultant who specialises in hip problems in young people.

A week before the appointment I rang the Learning Disability Liaison Nurse at BRI and explained that Rachel would behave better for a male radiographer and she does not wait very well. When we got there two lady radiographers met us – they had not been given my message!.

We then waited 90 minutes to be seen in clinic and then by a registrar who obviously did not understand Rachel's needs and barely interacted with her at all. He explained Rachel had a badly deformed hip but they would not do anything other than give her a pain killing injection – in 6 months time! I asked if we could pay privately to have the injection, but the private hospital he suggested wouldn't carry out the procedure.

I wasn't happy with this. The registrar had shown no willingness to interact with Rachel or support either of us with her increasing immobility and pain. She is now permanently in a wheelchair and has to be hoisted from bed to the chair and back to bed. Her quality of life is diminished .

I decided to ask for a second opinion and arranged a private consultation in Exeter. The surgeon had operated on other patients with learning disabilities before. He interacted well with Rachel and made a real fuss of her. He worked with us to support a Best Interests meeting where he clearly understood the impact Rachel's condition was having on her day to day life. We are hopeful that the operation will take place soon to give Rachel her spark back.

Looking back I wonder if my concerns had been listened to and if the first registrar had a better understanding of the challenges Rachel faced we could have saved a lot of time and trauma for her. If the Exeter surgeon says she needs a replacement hip – why did the Bristol one say nothing would be done – is it DISABILITY DISCRIMINATION?

Bronwyn

Rachel in her wheelchair

Healthcare after the Pandemic

Prior to the Covid-19 pandemic, people with learning disabilities experienced health inequalities which contributed to over 1,200 preventable deaths per year. These inequalities, together with the impact of the pandemic and increased concerns about delays accessing healthcare, make the health of people with a learning disability a significant concern. In this article our Childrens' and Young Persons Policy Lead, Gemma Grant, takes a look at how one area has responded to concerns around accessing treatment and the laws which should ensure easier access to healthcare for people with a learning disability.

Due to the health inequalities faced by people with learning disabilities in their local area, Calderdale & Huddersfield NHS Foundation Trust made a decision to prioritise people with learning disabilities for some types of treatment e.g. cancer care. This means that rather than waiting lists being based purely on the date the person was added to it, the Trust takes the person's learning disability into account making them a higher priority and leading to faster treatment.

This decision was made as women with learning disabilities die on average 20 years sooner than women in the general population and men with a learning disability die on average 13 years sooner than men in the general population. The Trust decided that *"the impact of waiting for treatment can further reduce this as well as disproportionately impact on their quality of life whilst waiting."*

Under a law called the Equality Act 2010, there is a legal duty for public bodies to make reasonable adjustments for people with a learning disability. Equality is not always about treating everyone the same – it is about treating people in such a way that the outcome for each person can be the same. Adjustments such as ramps to enable wheelchair users to access a building or allowing guide dogs to enter shops and restaurants are commonplace. However, adjustments can also be made to process and procedures to achieve equality of access. Prioritisation on waiting lists is a way of making adjustments to processes and procedures to improve health outcomes for people with learning disabilities.

Due to the challenges of the pandemic, there is a risk that the health inequalities faced by people with a learning disability will widen. We urge more Trusts to act on the evidence about the inequalities in health outcomes and prioritise access to treatment.

Our new **Health Resource** dealing with the specific challenges of overcoming barriers to healthcare following the pandemic is coming to our website soon. The resource was co-produced with family carers and forms part of a range of resources covering a wide variety of aspects health.

View our health resources here Health and Behaviour - Challenging Behaviour Foundation

Getting Support with Health Care

"Just having that ray of sunshine, being able to speak to someone, that actually gives you a direction ... that phone call, that guidance for me, that was hugely helpful."

Are you finding it hard to access support or get reasonable adjustments taken seriously? Our Family Support Team can help talk you through the steps you can take to get your concerns heard.

Our family support team are available 9am—5pm Monday to Thursday and 9am -3pm on Friday, give us a call on 0300 666 0126 or email support@thecbf.org.uk to find out what additional support we can offer.

Getting on with Glasses

We know that from a young age, having a learning disability comes with a much higher risk of having a sight problem and sometimes a serious one. But many sight problems are very treatable, and even if not, if we understand what a child or adult can see, we can help that individual make the maximum use of the vision they have. We asked SeeAbility's Head of Eyecare Lisa Donaldson to tell us a bit more about how to support someone with a learning disability to get an eye test and adapt to glasses.

Vision is so vital – up to 80% of our learning is based on it – it's a foundation of how we interact, how we get about, but it can be so easy to overlook. This is especially true for people with learning disabilities and/or autism given 'diagnostic overshadowing' where behaviours are wrongly put down to that diagnosis.

Of course discovering what a person can see means getting that all important sight test and I am sure there are some readers out there who have experienced problems with this! At SeeAbility our mantra is 'no one is too disabled for a sight test' – did you know, for example that you do not have to read or speak to have a sight test? As an optometrist, part of our 4 years of training and a requirement of our professional registration, is the ability to test sight and the health of the eyes without complicated machinery and without needing the patient to explain what they can and cannot see.

Of course once you have been able to support your loved one with a sight test, finding that they do need glasses may raise all sorts of understandable concerns. How will the person tolerate the feeling of glasses on the face? The change in what they can see? When to wear them and when not to? What about breakages and costs?

One of the most common responses I get from families is 'he/she will never cope with glasses!' But there are some tips and tricks that can help. In my work I can honestly say there are children and young people who no one ever expected to tolerate glasses who are now happily wearing them, indeed wanting to wear them! It can take some weeks or months, but is so worthwhile. See below for our teams' top tips on getting used to glasses.

Our teams "top tips"

Make sure glasses fit properly. They should fit on the nose, not slide about and fit on ears without hurting them. The person needs to be able to see through the middle of the lens. There is a whole profession of dispensing opticians who provide expertise in the fitting and support for glasses wearers. For children and those who are registered visually impaired it is actually a legal requirement that a dispensing optician is at least supervising the dispensing of prescribed glasses (although optometrists can also undertake this too).

There are glasses frames available that are specifically designed for children with complex needs and certain facial characteristics including very strong, bendy and flexible frames. There are small ear pieces that help stop glasses slipping from ears, adjustments that can be made for hearing aid wearers, or headstraps for glasses if a person's posture makes it difficult to hold their head upright.

Getting on with Glasses continued

A good local optical practice will be able to give you more information and advice from their dispensing optician, or see the SeeAbility website for signposting for optical practices that specifically list the support they give to people with learning disabilities. They should be happy to see how you get on and invite you to come back to make any adjustments needed if the glasses are uncomfortable.

Be clear as to what the glasses are for. Are they for all the time, or just near or far activities? Does everyone who supports your loved one know when they should be worn? If you have different glasses for different distances you could try different colour frames to identify, or stickers on the case with the activities they are mainly used for. That way you know that your loved one isn't being made to wear the wrong glasses for the wrong things which can be off-putting in itself!

Adaptation is key. For anyone with glasses, let alone people with sensory sensitivities, they can take a lot of getting used to. Your brain is working with your eyes to adapt to a very different view of the world, as well as the feeling of wearing them. Practice wearing glasses for short bursts, doing something that the person you support enjoys. So this could be going for a walk if a person is short sighted, so that they can see objects further away or supporting them with a liked near task (perhaps looking at a book together or using a tablet) if the person needs glasses for close tasks. Start for small regular amounts of time, for example just for 10 minutes 3 times a day to start with then extend it to 30 minutes over the weeks. Interestingly we have found it is often easier to help someone struggling with glasses to get used to them when active, rather than when sitting down. In special schools we or teachers walk with the child with each hand held – moving up and down the corridor or around the classroom when they get their new glasses. That has honestly worked a treat with some of the children we support, as well as working with occupational therapists in schools about ways to support individual children.

Another option for getting used to glasses can be to have a 'lens-less' pair that you use to just help the person get used to the sensation of the glasses frame, and this will also probably alleviate the worry of breakages at first. Your optician may also advise trying a weaker prescription at first, meaning the person gets used to a more subtle change in how they can see the world before moving on to their full prescription.

Be Prepared! Getting two pairs of glasses can also help so you have that spare pair in case of breakages or for one for home, one for school etc. Although there is no general entitlement under the NHS scheme you can ask your optician to apply for a second pair due to the special circumstances of the risk of breakages or problems with getting used to glasses.

Regarding costs, for children and for people on means tested benefits, you should be able to get at least some of the costs of glasses met through the NHS voucher system. To read more about this have a look at the NHS website. https://www.nhs.uk/nhs-services/opticians/free-nhs-eye-tests-and-optical-vouchers/

About SeeAbility

SeeAbility is a charity that, amongst other work, helps people with learning disabilities and/or autism get better eye care. The charity has been heavily involved in helping NHS England roll out a programme of sight testing and glasses dispensing in all special schools in England, after years of running their own projects and campaigning. Currently government support for this work has been halted and it risks being stopped or severely downgraded. Find out more about the project and how you can support it on the SeeAbility site here
Don't lose sight of doing what is right | SeeAbility

Investing in Early Intervention

Too often children with learning disabilities and their families are unable to access the early years support and services they need. Working with Cerebra, Council for Disabled Children, University of Warwick and Mencap, we have published a new report "Investing in early intervention" to raise the challenge of providing good early years support.

Many families of disabled children struggle to get the right early support in the right place at the right time – and this can mean that children's and families' difficulties get worse, unnecessarily. This report highlights how and why we should intervene early with targeted support for children with learning disabilities and their families.

Early intervention is about providing effective early support to children and young people who are at risk of poor outcomes. Supporting and working with the family is key for effective early intervention. Early intervention can take different forms, from helping a child to learn a key developmental skill (like early communication), directly helping to improve the well-being of the child's family, to programmes in early years education settings. Effective early intervention can make a real difference in both preventing problems occurring and tackling problems when they do start to emerge.

The importance of early intervention is recognised in a range of policy and guidance around support and services for children and young people with learning disabilities. Examples from practice also demonstrate how early intervention support can be delivered successfully to children with learning disabilities and their families in the UK to support prevention and a joined-up approach. Yet, too often it is not happening.

This report was developed by bringing together families, practitioners, and voluntary organisations - to look at the existing evidence and good practice to help "make the case" for early intervention support for children with learning disabilities and their families. In addition to making some key recommendations the report also pulls together the economic case for early intervention and the impact that the Covid-19 pandemic has had on children with learning disabilities and their access to support. The report is available to download from the Cerebra website. New report launched: Investing in early intervention - Cerebra Family carers can request a printed copy of the report from CBF call 01634 838739 or email info@thecbf.org.uk.

Are you up to date on your vaccinations?

As the winter sets in and concerns rise about the possibility of flu and covid rates rising we are all being encouraged to get a flu jab and/or covid booster to help everyone have a healthy winter. But how do you best support your relative to have their vaccination? Our information sheet developed specifically with covid vaccinations in mind, is a helpful reminder of support, tools and techniques available to help you and your relative access vaccines with as little stress as possible.

Our information sheet covers some areas that might be of use when navigating vaccinations for your relative, including how to prepare your relative, how to think about reasonable adjustments that could make the environment and process of receiving vaccinations easier for your relative, and how best interest processes can be addressed and followed to ensure your relative is supported properly to understand and consent to the procedure.

The resource is available from our website or a hard copy can be sent to you if you contact us on 01634 838 739 or email info@thecbf.org.uk.

Speaking Up About Advocacy

As many of us know all too well, when someone has a severe learning disability and cannot use speech to communicate, having someone who understands their form of communication in order to advocate for them is essential to ensuring their needs and wishes are recognised in their care and support.

Working with a group of family carers with extensive experience of providing support to their relative to advocate on their behalf, we are reviewing our advocacy resources to ensure that they meet the needs of families and professionals who provide advocacy services.

Our recent review of direct and family advocacy services includes a list of organisations who might be helpful if seeking independent advocacy. This is enclosed with this newsletter or available on our website. This has been produced in light of feedback from families that finding appropriate advocacy services for their loved ones can be challenging.

We are also putting the final touches to a co-produced resource for families about what good advocacy looks like, how it is delivered and what their relatives rights are to access it. Keep an eye on our website to find out more and sign up to receive your copy, or call 01634 838739 or email info@thecbf.org.uk.

Covid-19 and the “New Normal”

The Covid-19 pandemic has had a huge impact on the lives of people with learning disabilities and their family carers. To ensure the “New Normal” enables good outcomes for people with learning disabilities and incorporates learning from the pandemic, the CBF has been working with researchers at the Tizard Centre on a project exploring the impact of the pandemic on people with learning disabilities and their families and practical implications to improve support going forward.

As part of the New Normal project, interviews were completed with 11 family carers over Zoom during UK national lockdowns. Family carers shared what life was like for their relative during the pandemic. A range of challenges were highlighted, such as disruption to support and unpredictable occurrences like shielding, in addition to a range of things that helped, such as continuity of support and the ability to use direct payments flexibly. There appeared to be stark contrast in the experiences of people with learning disabilities during the pandemic and variance in support. Researchers are currently analysing data from the interviews and writing a report on the findings. We look forward to sharing more details on this with you soon! Another aspect of the project involved a survey of family carers, professionals, and organisations. On our website there are four short reports on the findings of the survey, covering: (1) Good practice examples, (2) Healthcare and mental health, (3) Social care, and (4) Communications and education.

Further details and the reports are available on our website.

Your question from the email network

My daughter's residential care providers seem reluctant to resume activities off site in the community.

Swimming seems to be a real problem.

I have recently been told that if she were to go swimming, she would need 2 staff as she needs full support for personal care, dressing and undressing etc.This is to ensure the staff member can change in private. Has anyone else had this problem?

It is so sad that after such a long time in lockdown when so many have had no opportunity for socialization, exercise, and meaningful activities there is such reluctance to resume day services.

It may not be as easy, but it is possible to get oneself dressed discreetly in the same space as another. See for example all those changing on public beaches or indeed in communal changing rooms. In terms of my experience - my sister's former care home was extremely reluctant to resume activities away from the home. I hoped this would change in her new place but, so far, not really. I took her swimming myself recently, it was heavenly. Just pick a quiet time out of school holidays if possible and enjoy!

My son goes swimming and has done for ages. He has two staff, one to help him change / dry / dress and the other to be in pool with him, so they need own changing room also. Ask for another staff person for this. Perhaps social worker needs to be involved to change funding.

I'm wondering what the process was with your daughter going swimming prior to lockdown? For example, was she able to go swimming regularly and if so, was it with just the one staff member supporting her? The thing is if your daughter was going swimming with just the one member of staff prior to lockdown, what has changed that she now needs 2-1? Or do you feel they're still restricting community-based activities because of the past covid situation and using the "2-1 support" as an excuse to not take her swimming?

Can your daughter reliably stay in a cubicle for changing, dry and dress herself and wait until carer returns, with carer in cubicle next to your daughter, so they can give reassurance and instructions, also hearing if cubicle door opens? We do that with one of our sons.

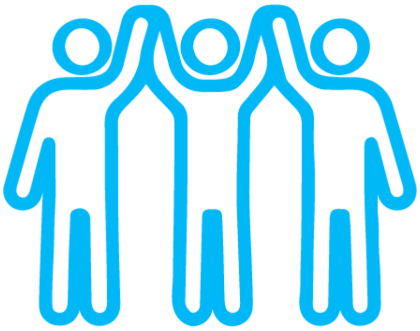
A carer can still change in complete privacy with a changing robe (gorilla robe or dry robe) are good. That way she can still be in attendance and with arms free!

Most disabled changing room or at least ours does, have a shower with a curtain that any Carer/ PA could use for privacy. Our staff if we ever have any change before they leave then they only have to change once when wet.

Our Family Carer Email Network is just one of the ways in which we connect families across the UK to share experiences, concerns and tips with others experiencing similar challenges. Email network@thecbf.org.uk or call 0300 666 0126 to find out more and be connected.

Find out more about peer support at the CBF http://bit.ly/PeerSupp

Do you need help with your family member's behaviour?



Are you unsure what services are available to support your family?

All behaviour happens for a reason and being aware of the reason is very important. There are three assessments that may provide further valuable information:

- You can ask your GP, CAMHS/CLDT or your Social Worker for a *functional assessment*. This assessment is carried out by a Clinical Psychologist or a Behavioural Specialist, jointly with the family carer and paid carers. It will look at what is causing the behaviour being displayed and identify ways for your family member to express their needs using different communication methods or different skills. The information gathered will be used to produce a Positive Behaviour Support Plan, with the aim of reducing the challenging behaviour.
- A *sensory assessment* may be useful in identifying if any challenging behaviour is due to sensory difficulties/differences and what can be done to help with this. This assessment is usually conducted by a Specialist Occupational Therapist. They may produce a sensory diet, which is a plan of how to meet the person's sensory needs without the need for behaviour that challenges.
- A *communication assessment* can identify specific difficulties and the most appropriate method of communication for your child. This is usually carried out by a Speech and Language Therapist (preferably with knowledge of Learning Disabilities). For sensory and communication assessments, a referral can be made by an SEND school or care provider and/or the GP.

How do you advocate for your family member to get specialist behaviour support?

You shouldn't have to manage all on your own – families have a right to support. It's known that there are effective ways to change behaviour and that it's best to start as early as possible. Services vary from area to area and it can take a really long time to get any help. A lot of families struggle to make people understand how much they need help and then to get any help; this is very frustrating and makes families feel more isolated. With the CBF's information it is possible to start to use Positive Behaviour Support yourself, but it is easier and more effective with professional input. To access help you could:

Use NHS Services If your family member is under 18, the local Child and Adolescent Mental Health Service (CAMHS) are the NHS service that helps children and young people with emotional, behavioural or mental health problems. The service may have nurses, social workers, psychologists and other therapists, who can assess your family member and offer some support or intervention.

If your family member is over 18, there will be an *Adult Community Learning Disability Team* or *Adult Mental Health Service* they can be referred to. Some areas have a dedicated behaviour team or Intensive Support Team to support people with learning disabilities who display challenging behaviour.

Advocating for your family member continued

Use specialist national services If you've been to a local team and they have done all they can for your family member, ask them to refer to a specialist service for further help. There are specialist national services for children and adults at the South London and Maudsley Hospital that local health professionals may be able to refer to.

Find independent specialist help If you find there is no local or national support available, ask if the school, care provider or respite service has access to a *behaviour specialist*. If they don't, the CBF have a list of independent behaviour consultants available on request that they could use to 'buy in' the specialist help. Some people may be able to choose to use behaviour consultants privately and pay for the service themselves.

Ask for the service you need locally Where an area has nothing available, people can ask the NHS to fund the health services they need. Write a letter to the Clinical Commissioning Group (CCG) to request a specialist in functional assessment to be made available as part of the local offer. You can contact the CBF Family Support Service for a template letter to help you and find the address of your CCG using this NHS Choices search tool.

Risk of admission to hospital

Sometimes a family members behaviour becomes too challenging for the people supporting them. If the situation gets to crisis, or the person is at risk of being admitted to an Assessment and Treatment Unit (inpatient hospital) you can:

Request a Care and Treatment Review (CTR) via Social Services or the Clinical Commissioning Group. This review brings in expert external input to plan what additional support could help the person with learning disabilities or autism and prevent them being admitted to hospital. See this information on CTRs, part of the national Transforming Care programme.

- Contact the CBF Family Support Service, who can support families of people with severe learning disabilities (SLD) who are at risk of admission to hospital (or signpost those who do not have a relative with SLD to other support).

New Team Members at CBF

(*From Left to Right: Helen Garnett, Taylor Anderson, John Prendergast, Daisy Fry, Kelly Horton, Amy Cue)*

There's been quite a lot of change at the CBF Office and we are delighted to welcome several new team members.

Joining the family support team are Amy Cue, Triage Administrator and Kelly Horton, Family Support Worker. Amy will be welcoming families calling our support line and directing you to information and support and Kelly will be directly supporting families with one-to-one casework.

In the policy team we welcome Helen Garnett and Daisy Fry our new Policy & Project Interns. Our interns work with us on a one year placement supporting projects and consultations as well as helping with the smooth running of the Challenging Behaviour National Strategy Group.

John Prendergast is a wonderful new addition to the Finance, Fundraising and Admin Team as Finance Assistant. We are delighted to have him on board to support the central team keeping the CBF running!

Our newest member of the team is Taylor Anderson. Taylor is joining us as Project Worker Engaging Young People. Taylor will be working on our exciting new project using direct engagement techniques to work with young people to inform our policy and influencing work.

We are so pleased to have such a great group of people joining us. We hope you'll get to meet them and hear from them in many CBF projects over the year.

Who's Who at CBF

Find out who's who at the CBF by visiting Our Team page on our website.

You can also remind yourself of our vision, mission and values.

If you want to get more involved in what we do, please consider becoming a volunteer. We are always looking for new Local Champions to join the team and help us to raise awareness of the work of the Challenging Behaviour Foundation, information and guidance about severe learning disability and challenging behaviour, and other related issues.

Go Gemma!

Gemma Harpum, our Family Support Lead, ran the London Marathon on 2nd October 2022. An incredible first marathon ran in 5 hours 38 minutes raising over £800 for the CBF. If you would like to show your support please visit Gemma's fundraising page here [Challenging Behaviour Foundation: Gemma Harpum (enthuse.com)]

In Memory

We have been honoured to receive donations in tribute to some of our good friends who we sadly lost this year.

We would like to extend our sincere condolences and sincere thanks to the friends and families of:

Robert (Bob) Corner
Peter Dickens
Kim Ruth Perez
Jan Seamer
and John Strachan

Jan Seamer Memorial Workshops

As many of you may know Jan Seamer had been involved in the CBF since our foundation and supported us in so many ways as a trainer and supporter.

In recognition of this we will be delivering a set of open access workshops for family carers in Jan's name. These will take place on the 13th January please email workshops@thecbf.org.uk to find out more.

Don't Forget the CBF 100 Club!

For £12 per year you will be entered into a monthly draw with the chance to win £25 each month or £50 in November. More info here: www.challengingbehaviour.org.uk/donate

Why not purchase a number, or two, as a special present for friends and family? To sign up please email: info@thecbf.org.uk or call us: 01634 838739.

Our 2022 100 club winners

Jan	Eileen Roe
Feb	Fiona & Simon Ingarfield
Mar	Steven Judd
Apr	Meryl Matthews
May	Sophie Twinn
Jun	Hilary Hawkins
Jul	Sophie Cooper
Aug	Christine Li
Sept	Neil Walton
Oct	Julia Genders
Nov	Anne Martin

Supporting the CBF

We rely on donations, grants and fundraising to continue our work helping families. Find out how you can help us at: www.challengingbehaviour.org.uk/get-involved or telephone 01634 838739.