

## Connections and Co-Production

Winter 2023

### Introduction

Welcome to this edition of Challenge – we are all connected in various ways to other people and places – with those connections varying in strength and importance. It is no different for children and adults with severe learning disabilities – sometimes these connections can be even more important for them. This newsletter is themed around connections and co-production – connecting to people and working together.

When you have a relative with severe learning disabilities who displays behaviours that challenge, it is important to connect to people who can provide practical information and support – and in turn for everyone to be “joined up”. Sadly, the education, health and social care system that we need for that support and those services is often fragmented and disconnected. Trying to find a way through it to connect things together to get the right support for relatives can be frustrating, time consuming and relentless. Everyone getting together as equals and jointly deciding what’s needed and how to proceed (co-production) is the way forward. It is likely to result in better outcomes, and we need to promote working together in this way.

This edition of Challenge provides some examples of great connections and joined up ways of working that deliver good outcomes for people and families. We share some practical resources, and families describe what has helped them to get the support they and their relatives need and have a right to receive. We know it’s not easy and that having someone that can provide timely, practical information and support is key. Our role at CBF is to help make those connections – between families, with professionals and across different systems – so children and adults get the support they need – in the right place and at the right time. I hope this edition of Challenge is helpful.



**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 01634 838739.

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Winter 2023

# Challenge

# Care for Family Carers

In the lives of their relatives, families are their constant. Teachers, social workers and support staff come and go, but families remain deeply involved and at times deeply concerned for their relative's well-being.

The system that families might expect to swing into action and support their relative is flawed, it's multifaceted and it's complicated. Navigating the system takes nerves of steel, tenacity and a lot of smiling through gritted teeth to achieve the right support, at the right time for your relative. The following examples show how we can support and work together with families (names have been changed).

## Knowing Your Rights

Anna came to the CBF when her 17-year-old Jake was in crisis. Alongside a severe learning disability, his OCD behaviours had taken over everyone's life. Although it was a difficult decision, the family knew that their son needed to move to residential care. However, being on the cusp of turning 18 meant that the Local Authority were unsure about where he should live. The CBF supported Jake's family to have conversations with professionals about what was possible (not just what was available) and what would work best for Jake. Crucially we helped Jake's family to understand his and their rights and how these were to be upheld even in the most difficult of times. About the support she received, Anna said:

**"It was all of that knowing where we stood, what rights we had, how to even send letters and how to put certain things in there."**

Jake is now living happily in a supported living service and has regular contact and outings with his family.



## Feeling Empowered to Complain

Six months and two flawed financial reassessments into a dispute with her Local Authority (LA), Edward's mum used the CBF's Disability Related Expenditure (DRE) [template letter](#) to complain.

The LA had gone back and forth on the decision to include essential expenses, including food for taking medication and transport costs for visits home, in the financial assessments. As a result, Edward was contributing more than he should towards his social care. Edward's mum complained about poor communication alongside concerns that the LA had not considered all of Edward's DRE.

The LA agreed there had been delays and unclear information, however, they said the DRE had been considered. Edward's mother, unhappy with the response, and supported by the CBF, asked the Local Government Ombudsman (LGO) to investigate. The LGO found fault by the LA which caused injustice. Recommendations included a request for a new financial assessment with consideration for all DRE which Edward's mother had provided. Further information on the complaint is available on the [LGO website](#).



## Seeking Legal Advice



Josh's family had purchased a home for him to live in. They hoped his lifelong friend might also move in. Despite having a wonderful, adapted property for Josh to live in, the Local Authority (LA) had been slow to finalise the support that Josh would need when he moved in. Like many families, Josh's family were confused by the processes that the LA followed.

After months of conversations and letters, the CBF supported his family to find a solicitor and joined meetings with them. This was instrumental in getting the LA's minds focussed on the outcome that the family were trying to achieve. Within a few weeks a provider had been commissioned and Josh moved into his new home. About the support offered by the CBF, Josh's mum said:

**"I came across the CBF purely by chance, in my desperation to find help and information. The CBF supported me in meetings, conversations with social workers, care workers, solicitors, helped to explain benefits and gave me emotional support when needed. It is down to the CBF that Josh is finally in his own accommodation, hopefully to be followed by his friend. We are so grateful to the CBF and the lovely, understanding staff."**

## Co-Producing a Lifelong Action Plan

In 2012, the Transforming Care programme was set up with the aim of moving all people with a learning disability and autistic people who were inappropriately placed in hospitals, out of these hospitals, and instead supporting them in their local communities. But over a decade on, we've seen multiple missed targets, promises made and broken, and over 2000 people still stuck in these hospitals. In July last year, the Government published the Building the Right Support Action Plan, which it said would deliver on the promises to transform care and support – but instead of having clear actions, monitoring mechanisms and an overall strategic approach, the plan was vague, disjointed and lacked accountability.

In September last year, a group of families of people who have been, and in many cases continue to be, failed by the current system got together to think about what would be needed in an action plan that would truly transform care. This plan aims to provide a strategic approach to not just getting people out of hospitals, but putting the right support in place so that no one ends up being admitted in the first place. From this start, a plan began to be co-produced – with families, people with learning disabilities, and people working across all parts of the system who want to see, and make, this change.



**"The care for individuals like our son is lifelong; it changes with their change and growth."**

– Family Carer

To create the change that we all want to see, we need a plan that takes a lifelong approach – looking strategically at all parts of the system and bringing them together to get things right at all stages of life. By sharing their expertise and their experiences, the people who have been involved in co-producing this plan have been able to identify not only what is needed, but how this can be achieved at all levels.

The plan sets out what the current issues are and what we need to see happen. It's split into two parts – actions that can be taken by the people who have worked to co-produce the plan, and actions that we need others, including the Government, to take.

Bringing together everyone to co-produce a plan means that the actions included are the ones that will make a real difference to people with a learning disability and their families at every stage. Rather than the current approach of looking at little pieces of the system without fully thinking about the bigger picture, this plan looks at the whole system first, with the rights of people with learning disabilities and their families at the centre.



This means moving away from crisis 'management' and instead focusing on preventing crises happening in the first place. It means early intervention and investing properly in community support that can be accessed as soon as it is needed – rather than only making the money available once someone with a learning disability has already gone through the hospital system. It means putting people with a learning disability first and providing rights-based, person-centred support, while also valuing and supporting unpaid family carers.

It also means working together – to come up with solutions, to carry out actions, and to support each other. The 'system' is complex, but it is interconnected. We cannot achieve change without all parts of the system working with each other, with people with a learning disability, and with their families. The co-produced plan is a joint effort between people who want to make meaningful change – we now need the rest of the system to join us in achieving this. You can read more about the action plan [here](#).

The plan is now being taken forward by the [Challenging Behaviour National Strategy Group](#), a group of over 90 core members who have significant knowledge and expertise, and a senior level role in supporting and delivering services to people with learning disabilities.



**“Working together we can drive this change – to really make a difference and deliver the outcomes we all want to see.”**

–Family Carer



## EARLY POSITIVE APPROACHES TO SUPPORT (E-PATs) RESEARCH STUDY

An exciting new research project is underway focussed on early support. The research is aiming to test whether a programme for families raising a young child (under 6 years of age) with additional developmental needs supports family carer well-being. Early Positive Approaches to Support (E-PATs) is an 8-week programme which was co-produced by family carers, Dr Nick Gore from the University of Kent and others including the CBF.

In E-PATs two facilitators, a practitioner and a family carer, work together and bring equally valuable but different perspectives to the sessions. The sessions cover an overview of some of the services that are available to families, the importance of looking after yourself as a family carer, and how to support sleep, communication and skill development with your child. In the later weeks E-PATs looks at behaviours that challenge. The fact that E-PATs takes place as a group is important as families have the opportunity to get to know and support each other and make connections with people they might not otherwise have the chance to meet. During the research study families will be chosen at random to attend E-PATs straight away or in 12 months. All family carers taking part complete some questionnaires 3 times and receive vouchers as a thank you.

Co-production has been part of the ethos of E-PATs from the start. The research has a Parent Carer Advisory Group that is supported by the Challenging Behaviour Foundation and chaired by a parent carer. The advisory group ensures that the family carer voice is central and valued and runs through every step of the research.

Over the next few months, the research team will be recruiting families to take part in the study in Barnet (Barnet Mencap), Carlisle (Carlisle Mencap), Croydon (Croydon Mencap), Belfast (Mencap Northern Ireland), Derry (Mencap Northern Ireland), Edinburgh (Kindred) and Newport (Newport Local Authority).

To find out more and to watch a short video from the Parent Carer Advisory Group visit: [Early Positive Approaches - Challenging Behaviour Foundation](#). Read more about E-PATs in our report "Investing in Early Intervention" here - <https://bit.ly/3Gx9XzG>.

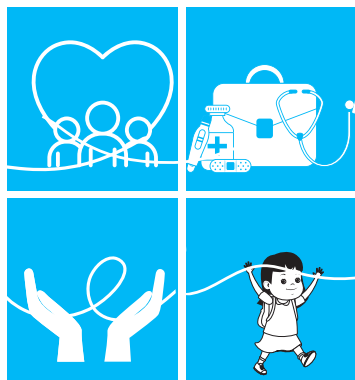
### **USEFUL RESOURCES**

Our report "Investing in Early Intervention" produced in collaboration with Cerebra, Mencap, the Council for Disabled Children, and the University of Warwick highlights key research and examples of early intervention in action.

In the London Borough of Newham co-production has been key.

**"Parents with lived experience are guiding other parent through the SEND system in Newham and taking them along the path that they have already walked themselves which is so powerful."**

To view the report in full, go to: [Early Intervention - Challenging Behaviour Foundation](#)



# The Power of Connection:

## Supporting Relationships for Individuals with Severe Learning Disabilities and their Family Carers

In the realm of caregiving, particularly for individuals with severe learning disabilities, the importance of connection cannot be overstated. The power of fostering connections holds a significant place, not just for the individuals themselves but also for their family carers.

For individuals with severe learning disabilities, the significance of establishing and nurturing connections is immeasurable. Such relationships go far beyond mere social interaction; they are the cornerstone of emotional well-being, personal growth, and a sense of belonging. For many facing the opportunity to form and sustain connections might differ due to various factors related to their disabilities. However, the impact of these relationships on their lives is paramount.

Research shows that people with a learning disability often experience loneliness and isolation. In 2016, Mencap published research on this issue and the headline findings were:

- People with a learning disability mostly name paid staff if you ask who their friends are.
- 47% of people with a learning disability spend most of their time at home.
- 64% do not see their friends.
- 1 in 3 people with a learning disability spend less than an hour outside their homes on a Saturday.
- 1 in 3 are worried about being bullied outside of their home.
- 39% of people with a learning disability take part in a social activity less than once a month.
- Mencap also found that, "In a recent survey of people with a learning disability 24% said they felt lonely 'a lot'. This compares to just 3.4% of the general population who said they felt lonely 'often or always'."

Connections provide individuals with a learning disability the opportunity to share experiences, feelings, and a sense of identity within their communities. Whether these connections stem from friendships, family relationships, or through support networks, they contribute to a more fulfilling and enriched life. These relationships are essential not only for companionship but also for empowerment, as they can enable individuals to better communicate their needs, preferences, and aspirations, empowering them to actively participate in their community.

Moreover, connections play a pivotal role in the emotional and psychological well-being of family carers. The responsibilities and challenges they face while caring for their loved ones with severe learning disabilities are immense and multifaceted. The emotional strain, coupled with the often-complex demands of caregiving, can take a toll. However, the support and connections within their own circles—be it through other carers, support groups, or extended family—can provide immense support and valuable insights.

While recognizing the significance of these connections, it's essential to highlight the challenges in establishing and maintaining them. Access to support services, societal attitudes, and a lack of resources can often hinder the development of these crucial networks. Collectively, we must endeavour to create more inclusive and supportive environments that enable and encourage these connections to flourish.

Family carers often find support, advice, and empathy through connecting with others who share similar experiences. These connections create a sense of community, reducing feelings of isolation and offering practical guidance in navigating the challenges they encounter. When services know how to connect with families, listen to them and explore solutions together, then the outcomes for individuals can be improved.

In recognition of the need for professionals to understand and reflect on how their practice supports a family centred approach, the Challenging Behaviour Foundation have developed a new workshop: Whole Family Approaches. Co-designed and co-delivered by professionals and family carers, it brings professionals together to engage in a reflective and practical course to improve practices around family centred approaches. The course brings together evidence-based approaches and practical knowledge and skills of family centred approaches and models partnership working.

During our workshops, Professionals can:

- Explore the lived experience of families navigating a system of support
- Identify what is a whole family approach and why a family-centred approach is important
- Understand the concept of institutionalising parent carer blame: findings from research
- Identify what is working in partnership from a family's perspective
- Consider their role in the development and support of a family centred approach as a support to families to decide what strategies will best suit them

A professional who attended this workshop said:

**“This workshop really makes me think about my practice, it's so powerful to hear from families with lived experiences not just professional trainers. I feel so much more confident and empowered to see things through the lens of family centred approaches.”**

The importance of connections for both individuals with severe learning disabilities and their family carers cannot be overstated. They form the bedrock of emotional well-being, personal development, and resilience. We can face difficult situations together with a positive approach that seeks to understand and support; where things are 'done with' rather than 'done to' people. As a community, we must recognise, support, and actively foster these connections to create a more inclusive and supportive environment for everyone involved. It is through these connections that we can truly enrich the lives of individuals with severe learning disabilities and create an equal partnership with families and professionals.

If you'd like to book a workshop or learn more, please email to [workshops@theCBF.org.uk](mailto:workshops@theCBF.org.uk).



# YOUR QUESTIONS FROM THE EMAIL NETWORK


*Hi, we have a severely disabled son who lives out of area 80 miles away. We are very happy with his new placement. Before he moved we had an advocate for our son, which we now want to reintroduce, but the Authority are refusing to pay. They say as we are Health & Welfare Deputies, we don't need an advocate. We found the advocate of great benefit to the well-being of our son and most definitely in his best interests as he is out of area. All we are asking for is a visit from the advocate say every couple of months or so just to keep an eye on things. Many Thanks, P*



*We too have just been through a court of protection case for my relative who is severely autistic and non-verbal. The Local Authority said he did not need an advocate and they did not have to fund one, but our solicitor said that people in supported living are entitled to an advocate. My relative was therefore awarded an advocate as part of the court of protection case. Hope this is of some help to you.*



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](mailto:network@theCBF.org.uk) or call 0300 666 0126 to find out more and be connected.



***Unfortunately, I think them's the rules. If you are a Deputy, you are the advocate and have no entitlement to independent advocacy. It is the downside of being a Deputy evidently.***

***So, there are limits to the advantages of going through all the rigmarole of becoming Court of Protection Deputies, no access to advocacy when you want and need it, and getting it foisted on you when you don't!  
Good luck!***



***You could offer to pay yourselves. It would be worth it. Ask an advocacy service if this can be arranged.***



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# Family Carer Advocacy Resource

Family carers of people with a learning disability – particularly people with a severe learning disability, or who are non-verbal – often find themselves acting as advocates for their relatives and being their voice.

Unlike many professional advocates, who are often only commissioned to be involved on a short term basis, family carers are there throughout their relative's life – but they don't receive training and have to learn how to navigate the system themselves.

The CBF has worked with family carers and independent advocacy organisations to develop a resource that can be used to help family carers to advocate for their relative and make sure that their relative's life is as good as possible. This resource brings together information that family carers told us was needed – information about laws and how the system works, their relative's rights, their rights as a family carer, and how these can be used to advocate for their relative.

This resource is split into four sections – 'Know Your Acts', 'Family Carer Rights', 'Living a Good and Meaningful Life', and 'Advocacy' – and includes videos and case studies. Access the resource through the link below.

## [Family Carer Advocacy Resource](#)



**“We have to scramble around for information when we are in the middle of a crisis.”**

- Family Carer

# What matters to me?

What Matters to Me is a developing project that the Challenging Behaviour Foundation is leading with a group of 12 wonderful young people aged 16-25 across the South East who have severe or profound and multiple learning disabilities. We are working with two project partner sites; Demelza and Ifield Link-16 to facilitate direct engagement work with young people and their families. The aim of the project is to use creative engagement methods to develop a solid understanding of each young person's complex communication methods and to ensure that, despite these complexities, their experiences, preferences and views are included in important decision-making processes. Through this project, the young people are provided with a platform to be able to influence during this crucial transition period of their lives as they progress into adulthood.

We will be co-producing a multi-media manifesto with the young people and their support circles, to showcase the learning of this project. By using film and photography we aim to produce an impactful insight into what really is important for young people with complex needs in transition and how to consult with them. We will demonstrate how to gain and share their experiences, preferences and views to positively influence their support and services, and the policies that affect them.

We have set up a network forum to create a platform to share updates as the project progresses, as well as providing good practice examples and relevant resources and information. You can sign up to the forum under the [What Matters to Me page](#) on the CBF website.

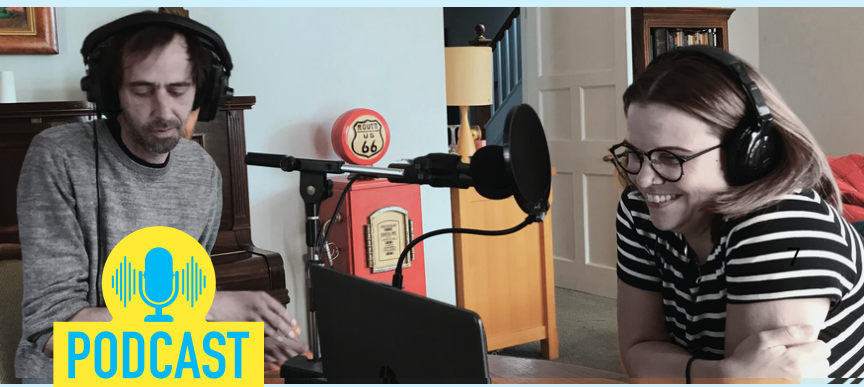


## Predictable and Preventable

### - How the system creates trauma

Following work with families about their experiences of trying to navigate the complicated system to get the right support for their relative- and how traumatic this is - we had a great opportunity to produce a short (12 minute) [documentary](#) with Kent University and KMTV. This film showcases the published research by Dr Peter Baker and colleagues which describes how the system that is meant to be in place to support families is in fact causing them to experience complex Post Traumatic Stress Disorder. Family carers share their experiences, describing the impact of constantly trying to understand and navigate systems and advocate for their relatives- and how easy it is for them to be labelled as "difficult parents".

Professor Luke Clements notes that this aligns with his work, describing how the system is currently arranged to operate in silos, which causes trauma. He explains that the solution is to change the system as this trauma is predictable and preventable. The film also references the co-produced Trauma Awareness workshops for professionals that was developed as a result of the research. The film highlights the importance of families and professionals working together as equal partners and understanding each other's perspectives. It also encourages professionals to be mindful of the impact of their interactions with family carers. For more information about the workshops, please email [workshops@theCBF.org.uk](mailto:workshops@theCBF.org.uk).



## Spinning Plates and Sharing Stories

Wellbeing is a word we hear and use a lot. We know it's important and covers a range of ideas from self-care, happiness, confidence, resilience, rest and relaxation but we also know that it's a tricky one to define and certainly one route to wellbeing does not fit all. How, for example, do you fit in a yoga session or even a cup of tea when you're caring for a child with complex needs? How do you build confidence and resilience to try another activity, or day out when there are seemingly so many challenges, and how do you find time for a moment for yourself, just a break, a breather, a bit of respite?

Of course, we don't have all the answers but as part of a project funded by The Coyer Fergusson Charitable Trust and some amazing Kent based families we have been investigating what the issues are and how we can better support carer wellbeing as an organisation. What we heard loud and clear is that families wanted opportunities to share experiences with others, had amazing top tips on finding little moments of peace in a hectic world and strategies for living life to its full. What they wanted was easy and flexible ways to engage with content to support them at times to suit them and in ways that were easy to combine with their day-to-day lives. We hit upon the idea of a podcast driven by families' experiences to talk about the real-life issues and experiences that impact on carers wellbeing.

Our new series of family podcasts 'Challenge Accepted' was launched mid-December and features family perspectives on connecting with others, taking time to themselves, spending time together as a family and accessing carers assessments and respite. The series of five episodes is available everywhere you can access a podcast from, and we hope you enjoy listening. Keep an eye on the CBF social media accounts for more information.



### Carers Assessment

At the CBF, we want to ensure that unpaid carers know about their right to support.

If you provide regular unpaid support to someone with a severe learning disability you are entitled to a carer's assessment, even if your relative doesn't live with you.

You can ask the social worker of the person you care for, for a carers assessment. In some areas a local carers organisation will complete carers assessments on behalf of the Local Authority.

**A carer's assessment** is an opportunity for you to express your views and concerns about your caring role. Things to think about before the assessment:

**List** of all the support you provide; keep a diary because you probably do much more than you think!

**How** does caring for your relative impact your life – are there things you would like to do but can't? Does it affect your relationships? Do you feel isolated or exhausted?

**What** would happen if you were unable to care due to an emergency – would your relative need support from paid carers?

**During** the assessment don't play down the impact caring has on your day-to-day life. The word assessment relates to your needs, it is not a judgement of your abilities

## If you are eligible for support the LA will develop a support plan, you could be entitled to:

**Practical support** such as a cleaner

**Emotional support** such as counselling

**Support for your wellbeing** such as social groups and activities that you enjoy doing

**Equipment** and home improvements

**Training** to help you care for your relative

**Extra care** for your relative so you can take a break

"That money is for you to look after you... you can use the money, you know, whichever way that supports your well-being that is agreed with the person (assessing), the process is quite smooth, you have a chat, you fill in a form. And so that's a very good thing"

- Eva,

speaking on the CBF podcast

"I asked for a carpet because my carpet was really, really old with my son spilling things on it. It made me feel so much better, just to be able to have a new carpet."

- Maria, speaking on the CBF podcast

For more information, please visit -

[Impact of caring on families - Challenging Behaviour Foundation](#)

[Carers assessment | Carers UK](#)

[Needs assessment | Carers Scotland \(carersuk.org\)](#)

[Carers assessment | Carers Wales \(carersuk.org\)](#)

[Assessments in Northern Ireland 2023-24 \(carersuk.org\)](#)

<https://cerebra.org.uk/download/getting-support-to-stay-in-work-and-to-take-breaks-from-your-caring-responsibilities-in-england/>

<https://cerebra.org.uk/download/getting-support-to-stay-in-work-and-to-take-breaks-from-your-caring-responsibilities-in-wales/>



# Peer Support Services

The CBF offers free peer support for family carers in your own homes. See below for some of the services we provide.

## Listening Ear Service

Sometimes, it helps to 'offload' to someone who understands what you are going through. These calls offer a listening ear, giving you the time to talk confidentially. This is not a counselling, information or advice service.

To know more or book a session, visit - <https://bit.ly/3tdWJot>

## Family Carer Email Network

Join our Family Carers' Email Network and get in touch with families around the UK to share experiences, get information and peer support.

<https://www.challengingbehaviour.org.uk/for-family-carers/family-carers-email-network/>

## Carer's Catch Ups

Informal peer support groups hosted by a family carer on Zoom.

You can chat with others who understand the ups and downs of caring for and about someone with a severe learning disability.

Visit here to learn more - <https://bit.ly/3tdWJot>

# Recruitment

## Join Our Team as a Workshop Facilitator!

- Are you a Positive Behaviour Support (PBS) practitioner or a family carer with a wealth of experience in caring for someone with behaviours that challenge?
- Are you passionate about sharing your knowledge and experience to help family carers and professionals better understand challenging behaviour?

The Challenging Behaviour Foundation is recruiting for our next cohort of Workshop Facilitators, and we want YOU to join our team! To learn more, visit

<https://www.challengingbehaviour.org.uk/join-our-team-as-a-workshop-facilitator/>





## Join our 100 club!

Our 100 Club helps fund our organisational costs like printing and postage. For £12 per year, you will be entered into a monthly draw with a chance to win £25 each month or £50 for the November winner. It also makes an ideal gift! More info, visit [www.challengingbehaviour.org.uk/donate](http://www.challengingbehaviour.org.uk/donate)

## In Memory

The CBF was very touched and honoured to receive donations in memory of:

**Jonathan Frances Winfield**

**Stuart Hill**

## Fundraising for free

Why not use Everyclick, Give as you Live or Easy Fundraising when doing your online shopping to support CBF for free.

[Click here to know more](#)

**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](http://www.challengingbehaviour.org.uk/get-involved) or telephone 01634 838739.**

This edition of the newsletter has been sent out electronically. To view past editions or to sign up a colleague to receive an electronic version, please see our [newsletter sign-up page](#). Subject to funding, we are sometimes able to send out a printed version of our newsletter, delivered directly to people's homes, for people without access to the internet. If you know somebody who wants to be added to the mailing list for future printed copies ask them to call us on 01634 838739.

Disclaimer: While every care is taken in the compilation of this newsletter, the Challenging Behaviour Foundation cannot be held responsible for any errors or omissions, nor accept responsibility for any goods or services mentioned.

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## Winners

May	<b>L Murphy</b>	Sept	<b>J Tame</b>
June	<b>E Cressey</b>	Oct	<b>C Lowe</b>
July	<b>Mrs Graham</b>	Nov	<b>M Wasilewsk (£50 winner)</b>
Aug	<b>Mr &amp; Mrs McMillan</b>		



Fundraiser: Helen Marron (CBF Finance and Fundraising Lead) will be running the London Marathon in April 2024, raising funds for the CBF. Please support her if you can. Visit [here](#) to know more. Every little helps.