

Challenge

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Health Matters

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<http://bit.ly/CBFNewsletters>

Everyone needs support in life – from family and friends, (which is essential, ongoing and constant) and from a range of professionals which varies according to particular circumstances. When my son was diagnosed with a severe learning disability, I relied heavily on the support of family and friends for both emotional and practical support- and I knew I needed support from “the system”, from the experts who could help me and my family to help and support my son.

I expected (wrongly!) that support from the system would be arranged in a way that was co-ordinated and joined up. Very quickly I learned that “the system” was complicated, there was no one way “in” and that it is in fact broken into multiple component parts, across education, health and social care, all with different eligibility criteria and access processes. It is not person-centred, family-centred or holistic – it is complicated to navigate, disjointed and families have to find a way to put the pieces together to secure the support they need and to make it work for their relative.

In contrast, Government policy says that support and services should be person-centred, flexible and tailored to individual need. Policy promotes early

intervention – getting support in place early on to prevent getting to crisis, planning ahead and valuing families as key partners. All very sensible - but for most of the families who contact the CBF the gap between policy and what should happen, and practice and what does happen, is huge – more like a chasm than a gap!

We know it is possible to support children, young people and adults with severe learning disabilities who display behaviour that poses significant challenges to us. Despite the complexities of “the system” there are families and professionals who are making it work. This edition of “Challenge” includes examples of both, as well as initiatives like STOMP and STAMP that have the potential to really make a difference if we use them, working together and supporting each other to drive change. In all aspects of our lives, health matters.

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



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

Tracey and Sky's Story

Tracey is a nurse and here she shares the story of her daughter Sky's experiences with over-medication in an ATU (Assessment and Treatment Unit) and a hospital setting.

When my daughter Sky was 16 years old she spent 15 months in an ATU in Birmingham. Sky was admitted to the ATU because she was hurting herself: biting and banging her head and doing this continuously 20 hours a day.

Despite the unit being for young individuals the ATU felt quite bleak: there was no colour and there didn't appear to be anything of interest around, a very non stimulating environment and quite shocking.

Due to Sky's agitation sedatives were administered but Sky is very sensitive to that sort of medication. Once given it would make her physically unsafe. She would be tottering around on her legs and really unsteady but it wouldn't slow down her brain and then she'd be given another sedative.

Before Sky was admitted I was told that the ATU would be great because it would be able to strip Sky's medication back and make some important changes for her quality of life. Sky was left on medication for months and the side effects were showing that it wasn't good for her. It was a fight to get her out of that environment.

Last year Sky was admitted to hospital as she wasn't getting enough oxygen into her lungs. Once she reached A&E she was given sedation because she would not tolerate the oxygen mask. So many different types of medication were given to her, as a mum and a nurse I was really quite concerned. Sky was having injections of Lorazepam, Ketamine and Midazolam and every time she woke up she was frightened, not knowing where she was. Seeing the oxygen mask on her face was really distressing for her so she would start hurting herself. Every time this happened she was given medication and I kept being asked "what do you sedate Sky with at home?"

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Tracey and Sky

Tracey and Sky's Story - Continued

On one particular night the attitude seemed to change from Sky not being given a lot of medication to being given quite a lot and then not waiting for the effects of one sedative before doctors were attempting to give another. That night I was concerned that something would go wrong because I knew what was happening was not right. Prior to this admission for Sky I'd never considered that she could go into hospital for something simple and end up in such a precarious position.

A lot of training and awareness is needed in hospitals because even with a communication passport my voice wasn't heard and Sky wasn't looked at as an individual. People were trying to do their best but I think you can see where things can go wrong.

All the things that are in place that give Sky choice, let her know what's going on, and make her involved in her life are the reasons why her behaviours are decreasing and medication isn't necessary.



Sky with Tracey's granddaughter Lily

Getting Support

"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? 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 Friday, give us a call on 0300 666 0126 or email support@thecbf.org.uk to find out what additional support we can offer.



STOMP and STAMP Focus Group

STOMP - Stopping the over-medication of people with a learning disability and autistic people

STAMP - Supporting treatment and appropriate medication in paediatrics

The NHS England (NHSE) STOMP and STAMP team had the pleasure of working with the Challenging Behaviour Foundation to run a discussion forum to understand families experience and hopes for the programme.

The pandemic had led to many people feeling that STOMP and STAMP had stopped or was no longer necessary. To ensure that this is not the case, STOMP and STAMP has been relaunched and remains an important part of the Long-Term Plan for the NHS. It was vitally important to listen to people with lived experience, families and professionals as part of our work to relaunch and promote STOMP and STAMP. It was equally important to understand experiences of the programme and to listen to peoples' aspirations for the future.



The overall NHSE vision for STOMP and STAMP delivery is to create consistent standards for holistic, person centred, structured medication review (SMR), ensuring that confident and competent professionals deliver quality of life improvements through the appropriate use of medication. It is envisaged that this work will lead to STOMP and STAMP being delivered to the same high-quality standards across all services that support people with a learning disability and autistic people.

Project Aim:

Since the launch of STOMP and STAMP there is a lack of evidence to suggest a significant impact on prescribing of psychotropic medications. The aim of this project is to review the current understanding of STOMP and STAMP within specialist providers, people with a learning disability and autistic people and their paid and / or family carers. This information will be used to develop a set of recommendations for STOMP and STAMP delivery and associated reporting standards. It will also aim to ensure this is captured in NHS Policy with a mandatory requirement for it to be delivered and inspected.

To support the relaunch, a discussion group was facilitated by CBF, with family members of people with a Learning Disability and or Autistic people, to discuss the projects Aim. All participants were chosen due to having lived experience of STOMP and STAMP. It was essential to ensure that co-production underpinned this work and remains at the centre of everything NHSE do.

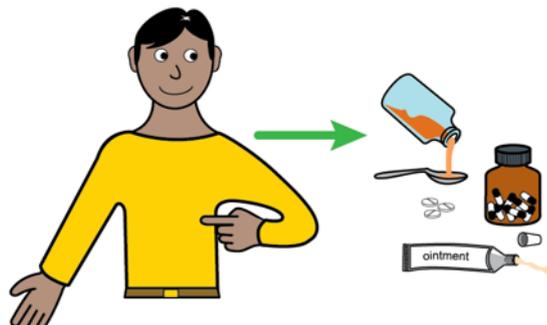
Overall, 13 families were represented at the session, which lasted for 2.5 hours, and included an introduction to the project by NHS England. The group were split into 2 breakout rooms and were asked to consider the following questions during their discussions:

1. What is your opinion and experience of STOMP and STAMP?
2. What do you think about our aims and objectives?
3. How can we get the right information from people in formal focus groups?
4. What would you want to see as a result of this work?

STOMP and STAMP Focus Group continued

Each group generated excellent discussion about the importance of STOMP and STAMP and gave thoughtful suggestions and ideas to the NHSE team.

The attendees within the group had varying experiences with their family members. They agreed that the principles of STOMP and STAMP were seen as much needed, however, it was felt they were far from being achieved. Several themes emerged from the discussions:



- The need for greater family involvement in decision making related to medication.
- Improved availability and use of alternatives to medication and preventative strategies instead of medication.
- The need to ensure holistic, structured and person-centred medication reviews are held regularly, and unnecessary medication is removed in a timely manner.
- The importance of support at times of transition to adult services.
- Clear and mandatory regulation and inspection of all health and social care providers to ensure they are held to account.

What happens next:

The session was inspirational to the NHS England team who also ran similar events with professionals and people with lived experience. All learnings will be captured as a set of recommendations to be considered as the next phase of STOMP and STAMP delivery, putting it firmly back on the agenda for all providers of care, commissioners and ICS leaders. We will continue to communicate and involve families in everything that we do.

A huge thank you to Coral, Elly and Daisy and all the inspirational family carers who attended an excellent event.

MindEd

MindED has training on stopping the overmedication of people with learning disabilities (STOMP). The CBF has supported family carers as co-authors to help write the session content for all ten modules. The first six of these modules have been launched with the final stages aiming to be launched in July. Family carers are currently supporting the filming and development of these final modules.

To access the training see: <https://bit.ly/3Ln1HEA>

Making Decisions about Medication

It is widely acknowledged that medication may be prescribed for people with severe learning disabilities, when they display behaviour that is challenging. It is important that families are provided with information to explain the medications their relative is taking when they are prescribed as they will be part of a decision making process when their relative lacks capacity to consent to the medication. When families are properly involved in the decision to prescribe medication and understand the rationale for prescribing it they can offer valuable feedback to the prescriber about the benefits and any side effects their relative may be experiencing. After all, they know their relative better than anyone else and in many cases are with them for most of the time.

Of course, at the CBF we agree with the NICE Guidelines which state 'Only offer antipsychotic medication in combination with psychological or other interventions'.

Wait, I have some questions!

It can be daunting to ask questions about medication. Some families tell us that they are not properly consulted when their relative's psychiatrist is considering prescribing medication and even when they are, they don't feel they have enough information to decide whether taking medication is in their relative's best interests. If your family member has been prescribed medication, we recommend asking the following six questions:

1. Has the person given consent, or does he/she lack the capacity to consent and if so, is its use in that person's best interest?
2. What are the reasons for the medication being prescribed?
3. What underlying condition is thought to be present and is it known to respond to medication?
4. What are the potential risks and benefits of such treatment (including side effects to look out for)?
5. How will the outcome be monitored? - how will we know if it is working and benefitting my relative, who will check, how will we check and when will we check?
6. For how long and at what dose will the medication be given and what reviews will be undertaken

What's in a name?

Families have also told us that it can be confusing to know what type of medication their relative is taking – often resorting to Google to search the name they have scribbled in their notes.

Every medication will have an official name, this is known as the generic name. If the medication is made by more than one company, it will also have a brand name. In the UK there are strict quality controls that must be passed before a generic or brand name medication is approved for use. This means they should be of the same quality and have the same effect, but it can lead to confusion!

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Making Decisions about Medication continued

When medication is received there will be a Patient Information Leaflet (PIL) in the packet with the medication – it is important to read this as it will tell you what the medication is for, and any side effects to look out for. If your relative lives in a residential service, you may not be the one who collects their medication and so you may not get the leaflet. If this is the case, you can visit the Medications and Healthcare products Regulation Agency (MHRA) website and search for the Patient Information Leaflet (PIL) at <https://products.mhra.gov.uk>.

The Challenging Behaviour Foundation has produced a resource on medications with Professor Tony Holland and Professor Ashok Roy. The resource provides an overview of five common types of medications that your relative may be prescribed:

- Antipsychotic medication
- Anti-depressant medication
- Mood-stabilizing medication
- Sedative and anti-anxiety medications
- Anti-convulsant and other medications

To see the full resource search for 'medication' on the CBF website, the information sheet is called 'The Use of Medication for Challenging Behaviour'.

The University of Birmingham worked with the Royal College of Psychiatrists and Mencap to develop some easy read information sheets for common medications prescribed to people with learning disabilities. The project has also produced audio versions of both the Patient Information Leaflets and the Easy Read guides. You can find these at www.birmingham.ac.uk/research/activity/ld-medication-guide/index.aspx or by typing 'Birmingham LD medication guide home' into Google.

Will we always need medication?

Your relative's medication should be reviewed regularly, and always if you are worried that they are experiencing side effects. Some families feel that whilst medication was the best option for their relative at the time, they would like to explore whether medication can be reduced or stopped altogether, especially if their relative's challenging behaviour is now better understood or if their support has improved. Others tell us that their relative is taking a lot of medications and they wonder if they are all necessary. Some families are nervous about reducing medication when their relative has been taking it for a long time. These are valid concerns and the person who prescribed the medication should be willing to discuss them with you.

The Challenging Behaviour Foundation worked with NHS England to develop an online Medication Pathway to support you to ask these questions to ensure your relative's medication is necessary and safe. The pathway covers topics such as:

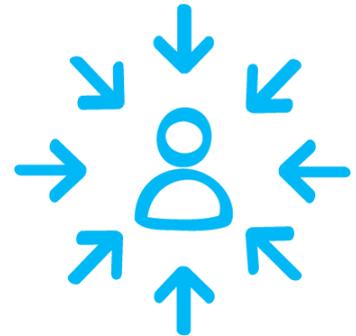
- What you need to find out before your relative starts taking medication
- What the alternatives are to medication
- How medication should be monitored
- What to do if you have concerns about your relative's medication.

You can find the Medication Pathway at www.england.nhs.uk/learning-disabilities/improving-health/stomp/ or contact the CBF on 0300 666 0126 for a paper version to be sent to you.

Reasonable Adjustments - a Case Study

In this article, Mandy Anderton, Clinical Nurse Specialist Learning Disability, and Fiona Armstrong, Consultant Anaesthetist, talk about the reasonable adjustments being made for people with learning disabilities at the Salford Care Organisation, part of the Northern Care Alliance.

People with learning disabilities experience higher levels of physical ill health and often present with complex and multiple health conditions, yet they face serious health inequalities and have lower life expectancy, dying on average 25 years sooner and frequently from avoidable and preventative conditions (Learning Disability Mortality Review Programme, 2020). An inability to express pain or general feelings of being unwell (or this resulting in behaviour described as challenging) can lead to delays or problems with diagnosis or treatment, identifying needs and providing appropriate care. People with a learning disability might struggle to engage with medical interventions due to lack of understanding or fear, whilst confusion amongst medical professionals about capacity and consent can all lead to further delays.



For some people with a learning disability, just travelling to the hospital for a general anaesthetic can be a frightening experience and potential barrier to support. Due to problems often experienced by people with learning disabilities to engage with medical procedures, like blood tests or having a scan, Salford Care Organisation (part of the Northern Care Alliance) has started to explore the use of deep sedation in the home to support people to have investigations, with the additional option of an anaesthetic if needed.

Under 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 necessarily about treating everybody the same. Rather, it is treating a person with a learning disability in such a way that the outcome for that person can be the same. In Salford, reasonable adjustments are being applied to the processes and practices of deep sedation and general anaesthesia to help support early medical diagnosis, intervention and equality for people with a learning disability.

Simon, a gentleman with severe learning disabilities and autism, has a longstanding fear of needles, medical professionals and environments. Blood tests, an echocardiogram and ultrasound scan were needed to help identify any underlying, and potentially serious, medical causes for his swollen ankles. Opportunities for desensitization had been exhausted and attempts to take blood with the support of regular oral sedation had proved unsuccessful. Working together and within the legislation of the Mental Capacity Act (2005), Simon's family, support team and health care professionals from both general health services and the Adult Learning Disability Team came together to form an individualised plan, which would enable Simon to have deep sedation (with the option of a general anaesthetic if needed) in his own home before being safely transported to hospital for further care and treatment.



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Reasonable Adjustments - a Case Study continued

Central to this plan was the application of reasonable adjustments—

- Administration of deep sedation in the home by a Consultant Anaesthetist prior to transfer by ambulance once sedated
- The option of having a general anaesthetic in the home if required
- Medical uniforms were not worn
- Simon's usual morning routines were respected and formed part of the plan, e.g. oral sedation was administered in Simon's morning drink by his support worker under the direction of the Consultant Anaesthetist, who remained out of sight at this early stage as to avoid any unnecessary distress
- The ambulance parked slightly away from the house and out of view until required
- Opportunities were taken to carry out other medical procedures whilst Simon was sedated, including administration of Covid and flu vaccinations

Whilst still in its early stages, this work is undoubtedly supporting people with learning disabilities living in Salford to access the medical care they need in a way that works for them, helping to support health equality for some of its most vulnerable residents.

Please note that names have been changed to protect the identity of the patient

To find out more about the Learning Disability and Autism Service at the Northern Care Alliance see:

<https://bit.ly/4226PVN>

The Salford Learning Disability Service are also on twitter: @SalfordLDteam

Reasonable Adjustments: Resources on the CBF Website

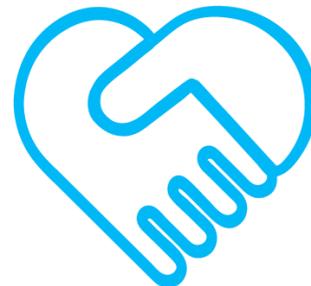


The CBF website has a topic sheet which addresses problems accessing health appointments and how health professionals can make things easier. The page also has a links to other useful resources including Health Action Plans, communication passports, what counts as a reasonable adjustment and information about the Equality Act and direct and indirect discrimination.

To read more go to: <https://bit.ly/3VdW0Nn>

Peer Support

The CBF offers free peer support for family carers in your own homes. The 'Carers' Catch Ups' and Listening Ear Service are open to parents, siblings or other close relatives of children, young people or adults with severe learning disabilities who display behaviour that challenges.



Carers' Catch Ups

The Carers' Catch Ups are informal peer support groups hosted by a family carer on zoom.

The general sessions enable you to chat with others who understand the ups and downs of caring for and about someone with a severe learning disability.

The focussed sessions give the opportunity to chat with others about a particular topic; share your experiences and hear from others about theirs.

Listening Ear Calls

The listening ear calls are support calls from a fellow family carer who is trained in active listening.

As a family carer, facing constant challenges can leave you feeling tired, frustrated, and helpless. Sometimes it helps to 'offload' to someone who understands what you are going through. This is not a counselling, information or advice service—these calls will be purely a listening ear, giving you the time to talk. The support is non-judgmental and confidential.

The CBF Family Forum

The CBF Family Forum is a private Facebook group for family carers of children and adults with severe learning disabilities whose behaviour challenges. The group moderators are CBF volunteers and family carers. The group is a welcoming and supportive community, with opportunities to share personal experiences, ask and answer questions, and form relationships with one another.

For more information, including the timetable for the upcoming general and focused Carers' Catch Up sessions see the Peer Support page on our website:

<http://bit.ly/PeerSupp>

For more information on booking a listening ear call:

<https://bit.ly/3Lvx3HT>

If you don't use the internet and would like to book a Listening Ear call please call 0300 666 1026 and Amy, our Triage Administrator will be happy to book you in.

For more information on the CBF Family Forum Facebook group:

<https://bit.ly/CBFForum>



Your question from the email network

Can anyone advise if they have experience of Lamotrigine or Lithium Carbonate for their loved ones, please?

My son has been recommended one or the other and he is already on Risperidone and Conazepam (the clonazepam will be titrated down).

The rationale is that one of these meds will help with extreme mood swings and challenging behaviour. But my son challenges usually for a reason - either health issues or because he cannot express his needs even though he is verbal.

Sorry to hear you are going through this, I know how heart-breaking it all is and the worry it causes.

My son takes Lamotrigine but for seizures not behaviour. It does not seem to have a positive effect on his behaviour. He also takes Epilim for seizures in addition to Lamotrigine. He has very challenging behaviour at times, he is 26 and very strong. He has never been medicated for behaviours and I think it's about getting the correct support in place, in the right environment. As you say his behaviours are for a reason if we don't always know.

I do think overmedication is an issue and may not solve the problem anyway.

I'm sorry to hear that your child's experiencing difficulties. My son takes Lamotrigine for epilepsy not in terms of behaviour. I know that his other epilepsy medication - Epilim - is supposed to have a mood stabilising effect? Not sure about Lamotrigine?

I'm working on diet at the moment and increasing my son's slow burn carbs and protein. We have really hit a sweet spot at the moment with much better regulation. I found the info on Spectrum news re low blood sugar and behaviour - might be worth a look?

I would recommend great caution with lamotrigine.

My son was prescribed it for epilepsy but as soon as the dose went above 50mg he became aggressive, and his support staff said it had altered his behaviour.

We quickly reduced the dose and eventually swapped to Lacosamide and the aggression stopped.

I haven't heard of the drugs you quoted but years ago my son already on risperidone was, due to a rise in challenging behaviour, put on quetiapine but as I was unhappy about him being on 2 antipsychotic drugs, I was assured they would be taking him off risperidone, but he remained on both for several months. His behaviour escalated. So, my advice would be to make sure to check they follow up on withdrawal of the first drug. I had a similar disaster with Lorazepam as they were not using it as a p r n drug but giving it daily having decided that anti psychotics were doing no good.

Lamotrigine for seizures is our experience. Awful to start with but excellent for 4 years. Now on the medication merry go round since 2013. Son remains on Lamotrigine as it was a drug that was undoubtedly positive for him. But we have risperidone, topiramate and sodium valproate now.

The Lamotrigine was no longer keeping the tonic clonic seizures at bay. It made him much more relaxed and responsive partly because he no longer had night seizures and could get a good night's rest.

Both risperidone and topiramate interfere with the ability to ejaculate which our son finds very frustrating. Lamotrigine doesn't and no weight gain either.

Challenging Behaviours happen for a reason but when there is not stability and consistency and open communication with those providing the support the triggers may be forever present.

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.



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.

For printed newsletters please call us on 01634 838739.

Fundraising

Amy Cue, our Family Triage Administrator, took on the Virtual Shires Challenge (Lord of the Rings) to raise funds for the CBF. Amy raised £100 for the CBF!



Congratulations to Ben (and his dog Woody) who recently completed a sponsored walk. This is such an achievement for Ben and his staff team and the walk raised £50 for the CBF!

Simon Histed ran the London Marathon on Sunday 23rd April. Coral Histed, our Adult Policy Lead, ran a London Marathon 'Rejects' run to raise funds for the CBF. So far they have raised over £500! It was a first marathon for both of them, such a fantastic achievement. If you would like to make a donation, please use this link:

<https://cbf.donr.com/simonandcoral>



100 club winners



Dec 2022	Mrs T Bigham
Jan 2023	K McMillan
Feb 2023	S Judd
Mar 2023	A Martin
Apr 2023	V Birchall

Don't Forget the CBF100 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.

Donations

We would like to thank all those who have made one off donations, supported our fundraising challenges and those who continue to support us by regular donations. We couldn't do what we do without your support. It is greatly appreciated.

The NHS England STOMP and STAMP team have had the pleasure of working closely with the Challenging Behaviour Foundation to further awareness and understanding of the programme. It is our pleasure to have provided funding to support the development of this excellent newsletter which we hope you will find informative and beneficial.

STOMP and STAMP

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.