Challenge

Winter 2020 Registered charity no. 1060714

The Challenging Behaviour Foundation

Your rights during difficult times

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

What's in this newsletter?

Welcome to the latest CBF newsletter.

Over the winter months the national pandemic arrangements are ever changing and continuing to affect everyone's daily lives. Living with uncertainty is difficult at any time, especially when you support a family member with a severe learning disability whose behaviour challenges. I know from my own experience with my son that as a family we have had to learn to respond swiftly to unexpected changes and new challenges, but Covid–19 has introduced a whole new layer of unpredictability. This newsletter contains a range of information we hope will be practical and helpful; from joining online Carer Catch-ups with other families in similar situations who understand, to managing risk – in ways that activities can still take place, but with reasonable adjustments to manage and minimise the risk.

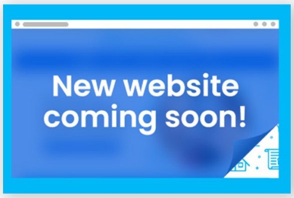
We know from all of our work with families that feeling isolated and alone is common - and that it is hard to find information that is practical and tailored to the needs of families supporting children and adults with severe learning disabilities whose behaviour challenges. The current pandemic has made life more complicated for everyone and increased concerns and worries about our relatives. One family carer shares her experiences on page 8, and this newsletter contains information about a range of ways we hope to help with this. There are reminders about our helpline support and new online resources, as well as summaries of information for families who do not use the internet and who may be feeling even more isolated as more and more contacts, groups and information are provided online. Although all CBF staff are working from home currently, we can still post resources and information to families so do ring us if you need hard copies.

These are difficult times – do get in touch for information or support.

Vivien Cooper
Family carer and
CEO of the CBF

Resources in this issue

All the resources featured in this newsletter (and more) are available on our website: www.challengingbehaviour.org.uk/



Also look out for our new website coming soon, funded through our 3 year project with the National Lottery Community Fund.

We are currently working very hard to get a brand new website up and running. There will be a new design to make finding information easier and improvements to accessibility.

This includes improving how we share resources so you can get the information you need more quickly.

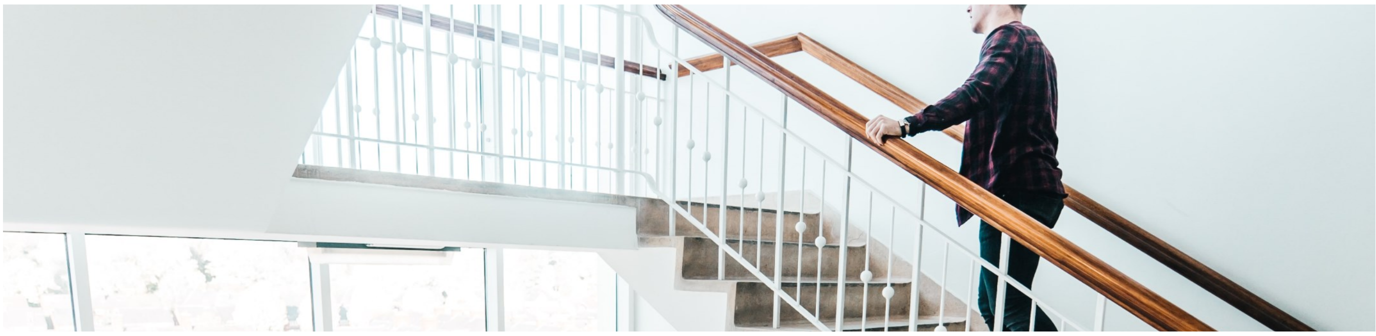
Who are the CBF? We are a charity supporting families of children, young people and adults with severe learning disabilities whose behaviour challenges.

Positive risk taking: maintaining quality of life during the pandemic

There are risks in everything we do and we all negotiate these risks all day every day without thinking about it very much. Risks can be high, low, or negligible, both in terms of likelihood and in terms of impact. Risks are mostly managed routinely (for example holding onto the handrail while walking up the stairs) but even high risks can be managed safely (for example - skydiving is high risk in terms of potential impact if something goes wrong, but the safety measures are stringent, so the likelihood of something going wrong is very low).

The challenge during this pandemic is that we are all rightly focussed on keeping safe from Covid-19 and some of the activities which were previously clearly on the 'safe list' (e.g. holding onto the handrail up the stairs) now hold a potential risk of infection.

But these must be weighed against other risks (for example, for someone with poor balance, the risk of a fall may be greater in terms of impact and likelihood and they could easily manage the risk of the handrail through sanitising their hands).



Key principles

- Risk management is a process to identify potential risks, eliminate, minimise, mitigate and manage them to ENABLE things to happen safely rather than PREVENTING them happening.
- The key principle should always be to go with the least restrictive option that successfully mitigates any risks.
- Activities, attendance at school, attendance at services or participation in activities should never be denied to people because it is "too difficult" due to complex support needs or challenging behaviour.
- The focus should always be on what is best for the individual and how to make that happen.

Information sheet

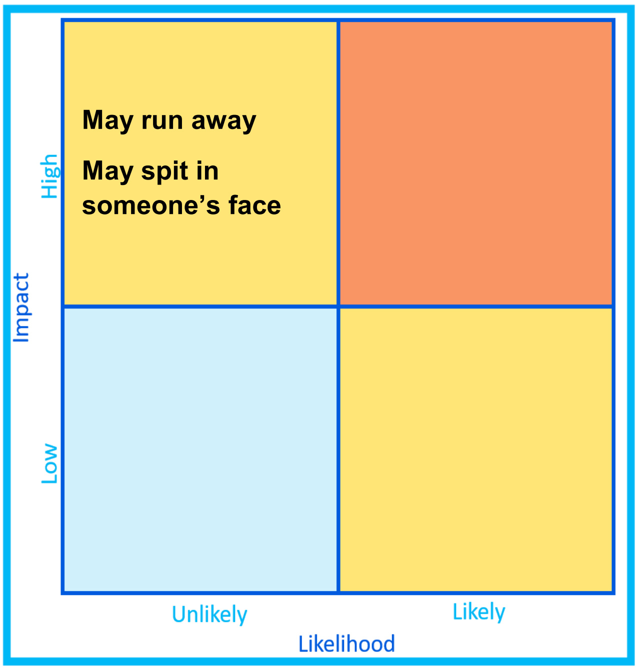
We are developing a new information sheet on positive risk taking which will set out the steps to follow to help enable activities to happen safely.

One of those steps is to clarify the risks of engaging in the activity as currently planned. It is useful to estimate both the likelihood and the potential impact of these risks, perhaps completing a matrix that rates likelihood (e.g. unlikely, possible, likely) and the severity of impact (e.g. minimal, some, severe). Similarly, clarify the risks of not engaging in the activity. It's easy to forget this as the risks may be less concrete and more long-term.

(With thanks to Prof Peter McGill for input to the forthcoming resource)

Positive risk taking: maintaining quality of life during the pandemic - continued

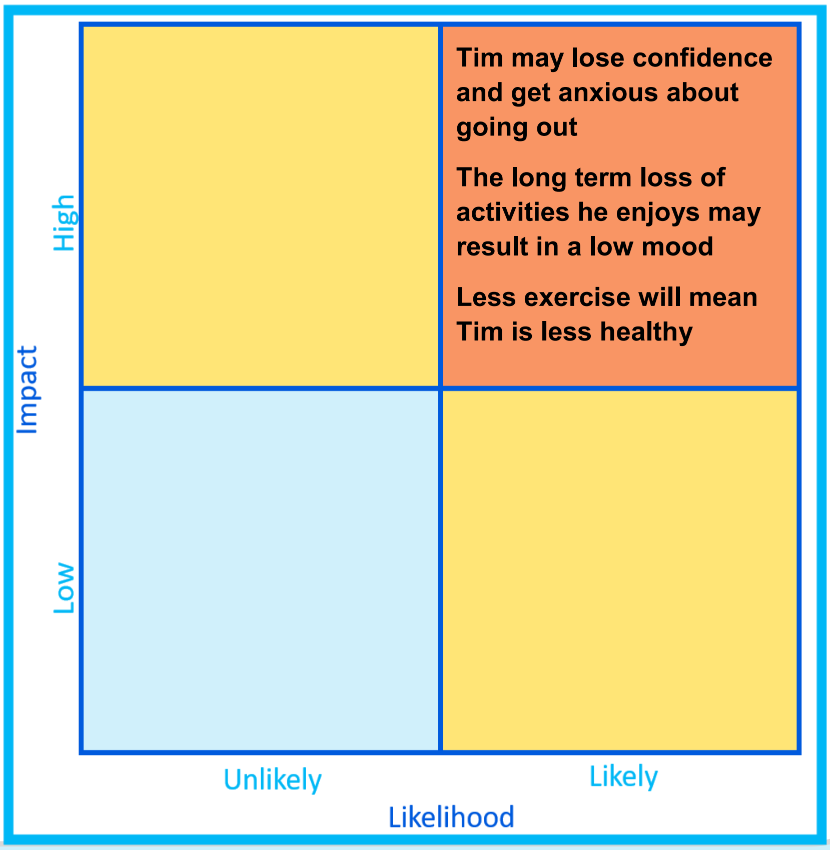
For example, the charts below show the risks associated with both taking Tim to the park and not taking Tim to the park. You can see that some previous behaviours would be concerning were they to happen at the park, but these behaviours are very rarely displayed by Tim (usually when in extreme distress) and his family and support workers are easily able to identify ways to mitigate those risks. However, the risks associated with stopping visits to the park are both significant in their impact on Tim's quality of life and very likely to occur. Following this analytical approach helps to get risks into perspective and shows that often not doing something can have a greater impact on an individual than doing it in a well-managed way.



Impact	Unlikely	Likely
High	**May run away** **May spit in someone's face**	
Low		

Risks of taking Tim to the park (chart 1)

Risks of not taking Tim to the park (chart 2)



Impact	Unlikely	Likely
High		**Tim may lose confidence and get anxious about going out** **The long term loss of activities he enjoys may result in a low mood** **Less exercise will mean Tim is less healthy**
Low		

How the pandemic has impacted the health of people with learning disabilities

We know that people with learning disabilities have been vulnerable to the Coronavirus pandemic, but this is not only due to biological risk factors. This article will discuss the reasons for increased risk of Covid-19 and the impact the pandemic has had on physical healthcare overall for children and adults with learning disabilities whose behaviour challenges.

Families have told the CBF that, early on in the pandemic, they were worried about their relatives with learning disabilities contracting Coronavirus. Some people were shielding a family member at home due to underlying health conditions. Some were concerned about the high rate of the virus in care services and the lack of PPE (Personal Protective Equipment). Sadly, these concerns were valid as the early stage of the pandemic saw high numbers of disabled people get Covid-19.

Existing risk: premature deaths of people with learning disabilities

Pandemic risk: increased number of people with learning disabilities have died during the pandemic

The Care Quality Commission (CQC) found that between 10 April and 15 May this year, 386 people with a learning disability died, compared to 165 for the same period last year (a 134% increase). Of those 386, 206 were as a result of suspected and/or confirmed COVID-19 and 180 were not related to COVID-19.

More figures on the pattern of deaths during 2020 are expected from the Learning Disability Deaths Review (LeDeR) and CQC.

Existing risk: inappropriate decisions at end of life

Pandemic risk: increased use of ‘Do Not Attempt Cardiopulmonary Resuscitation’ decisions

Due to concerns about how Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decisions were made for people with learning disabilities earlier this year, the CQC are reviewing how these decisions were used during the coronavirus pandemic. They will look at whether people were subjected to DNACPR decisions without their consent or enough information and support to allow them to make an informed decision. This suggests that yet again the Mental Capacity Act has not been adhered to by health and social care professionals and basic human rights of people with learning disabilities have been infringed. The CQC will report in early 2021.

What might help

We have an information sheet that sets out a range of practical ways to prepare for admission to hospital for treatment, a hospital stay and returning home. See: https://bit.ly/3n7o1Ek

If you do not have internet access and / or would like a free printed copy, call: 01634 838739.

How the pandemic has impacted the health of people with learning disabilities - continued

Existing risk: barriers to accessing healthcare

Pandemic risk: increased difficulty accessing healthcare

Anecdotally, the CBF know that families were already finding it difficult to arrange the healthcare their family members needed, and this became even more challenging during the pandemic as most non-emergency appointments were unavailable. People with learning disabilities have been left without any access to investigations or treatment. This is particularly hard for people with severe learning disabilities, who may not understand why they are in pain or feeling unwell or how long they will suffer for. Challenging behaviour is likely to increase when a child or adult is in pain or unwell; leading to a cycle of more difficulty in accessing any healthcare that is on offer.

Hospital and GP appointments changed from face-to-face to remote consultation during the pandemic. This may be easier for some people with learning disabilities, but harder for others.

During these difficult and confusing times it seems disabled people have been at the back of the queue for healthcare. The Equality Act gives disabled people the right to reasonable adjustments to enable them to access healthcare, however adjustments have not been made and people have faced discrimination. NHS Trusts have been asked to enable the most vulnerable people to access health services now that they are 're-opening'. We all need to work to ensure this happens and ask questions when it does not.

Existing risk: ongoing inequality for people with learning disabilities

Future risk: people will continue to face inequality if nothing is done to improve access to healthcare and decision making

Several organisations are focusing on these health inequalities: the CBF continue to raise the issues on an individual family level and at national policy level; Mencap's 'Treat Me Well' campaign is producing a report and CQC's reviews are ongoing.

Please contact the CBF's Family Support Service using

support@thecbf.org.uk

or 0300 666 0126

if your family are experiencing difficulties or delays in healthcare.

What might help

Learning Disability nurses can provide valuable information and support. Our information sheet sets out how Learning Disability nurses can help and how you can get in touch with one: https://bit.ly/3li0Zds

If you do not have internet access and / or would like a free printed copy, call: 01634 838739.

Frequently Asked Questions About Healthcare

There are some healthcare questions which are frequently asked and we have provided answers to these with links to further information. Other FAQs are on our website: https://www.challengingbehaviour.org.uk/health-challenging-behaviour/health-faqs.html

If you have unanswered questions after reading this information please contact us for individual support. Please contact the CBF's Family Support Service using support@thecbf.org.uk or 0300 666 0126.

FAQ: "We find it difficult to go to health appointments – what should health professionals do to make it easier?"

A: If your family member displays challenging behaviour, you might find it difficult to book or get to healthcare appointments, to get tests done or even to get the treatment your relative needs. The difficulties may be because your relative cannot tell you how they feel or finds it hard to cope with new places, new people or with waiting. If healthcare staff don't understand or respect people with learning disabilities, or if the health service is inflexible, then getting healthcare can be even harder. Here are some of the things you can do to make things easier:

1. Ask them to *listen* to your ideas and tell them about what the individual might find stressful during appointments to make things easier for everyone. Health professionals and NHS support staff (e.g. receptionists) should *support all patients* to access healthcare and be *flexible* to meeting the specific needs of patients with learning disabilities. They should listen to what parents or carers say. To help with this, people can have their own *Health Action Plan* and/or *Communication Passport*. Always take the communication passport to all appointments.

2. You can request '*reasonable adjustments'* to enable easier access to services for your relative. The Equality Act 2010 says that service providers, including hospitals and GP surgeries, must take reasonable steps to remove barriers which stop disabled people from having access to the same healthcare services as everyone else. Examples of adjustments which service providers can make include: early or late appointments, longer appointments, somewhere quiet to wait, priority appointments, easy read information. Also, when being referred for tests by a GP or other specialists, ask them to include any reasonable adjustments they might need to make in the referral letter. Disabled people accessing health services are also protected from *direct* or *indirect discrimination* by the Equality Act 2010.

3. Ask if there is a *Learning Disability Liaison Nurse* (LDLN) who can help plan a hospital or GP Surgery visit. LDLNs are specialist learning disability nurses and they have a better understanding of the needs your relative may have. They may be able to co-ordinate between different health professionals and might be there at the time of the appointment to help with anything extra needed on the day.

CBF resources - accessing healthcare

Accessing health care during the COVID-19 crisis can be difficult. It is understandable to be concerned about the idea of visiting a GP surgery, going to the dentist or having to attend a hospital appointment at this time, but it's really important that you do seek medical attention if you or your family member need it. Below are highlights from our information sheet 'Routine health care during COVID-19' available at: https://bit.ly/CV19infoIS

If you do not have internet access and / or would like a free printed copy of this resource, please call 01634 838739.

NHS staff are very busy with the COVID-19 crisis so it's especially important to be prepared for any health intervention that your family member may need. Tips are:

- Update or create their hospital/health care passport.
- Update or create a communication passport.
- Think about the 'reasonable adjustments' that your family member may need to help them to access good health care and ensure these are documented in their passport.
- Make sure that any medication changes/ allergies/adverse reactions to medication are recorded in the hospital/health passport.
- Make sure that other family members and support staff know how to access these documents/have copies just in case you become unwell/need to self-isolate or cannot attend a health appointment with them because of your own health risks.

If your family member needs help with something that is not a medical emergency, you should call your GP when the practice is open or the NHS 111 service if 'out of hours' in the usual way.

Most GP practices will take down the details and ask a practice nurse or doctor to call you back and assess the situation. Things like a consultation about medication may easily take place in this way.

Some GPs are able to set up a video call with their patients so the medical consultation can take place 'face to face' or refer to a hospital doctor who can do the same, so you won't necessarily have to take your family member in to any health facility.

However, if the health condition needs further investigations such as a blood tests, an X-ray or a scan for example, it is important that your family member still attends these. The GP/hospital will give you clear advice to follow to help keep your family member and those attending with them as safe as possible.

Remember! It's really important that you report any possible symptoms of COVID-19 prior to going to the GP surgery or hospital.

If your family needs emergency care call 999. All ambulance crews will be ready to deal with any health emergencies and be fully equipped and trained to manage the risk of COVID-19 whilst doing so.

Remember that failing to call 999 if someone has urgent health care needs can be far more dangerous for them if you do not seek help because of a fear of COVID-19.

The reality of lockdown for my brother and our family

My brother (54) lives in residential care and has a severe learning disability and hydrocephalus. This means he has severe brain damage, is in a wheelchair and because his head is enlarged his chin is often on his chest as he struggles to lift his head. My brother's main form of communication is touch, he needs you to come in close to him, catch his gaze and speak close to his ear whilst you hold his hand.

Since March I have only seen him 4 times, at a 2 metre distance and I can't touch him. My brother cannot see me at this distance and is not aware that I am there. Since a local lockdown was imposed I have had to sit outside whilst he is inside behind a window. I call his name, desperately waving to him, but he can't see me and appears confused and distressed. This leaves me feeling distressed, he looks so sad and I can't reassure or comfort him. All my life I have looked out for him, protected him and now I can't reach him.

I've tried video calls – he can't understand them. I've sent postcards, hoping the busy staff will read them to him. We cannot communicate via telephone as he's unable to respond. I'm sure he feels abandoned. I am appalled that I'm not allowed to see him and have meaningful contact. My brother has rarely been out of the home in 7 months.

No one has been allowed in to check that he is safe and well.

We have all had to follow restrictions, but anyone of us has been able to go to the shops, exercise and have some kind of life. My brother and lots of others like him have had this freedom of liberty taken away from them, without anyone batting an eyelid!

Celebrities on TV can form a 'bubble' so they can present TV together. Other people can go for a meal, to the pub….but I cannot visit my brother? Because he lives in a care home his choices are taken away from him.

Blanket bans on care homes need to be stopped.

The Government needs to put into place clear guidelines for our most vulnerable in society. Individual risk assessments should be undertaken, upholding their human rights and keeping them as safe as possible, whilst giving them contact with loved ones. There is no point in protecting them from the virus when they are dying from lack of physical contact! Physical contact is a basic necessity. To imagine life without a hug, without touch from your loved ones is just unbearable.

I work in the NHS so am well aware of the precautions and the need to reduce the risk of Covid. I am tested twice weekly, I deal with patients day in, day out in full PPE, but I'm unable to have that same contact with my dear brother.

My brother's prognosis is poor so we do not know how long we have left with him. Our family want quality of life for my brother, not for him to merely exist. Currently he is locked in his bedroom for 14 days as another resident has tested positive for Covid. He is imprisoned in his own home. How long is this going to go on for? We need to learn to live with Covid and look at ways of having meaningful contact with our loved ones as safely as possible.

My brother has no voice, but he deserves freedom. This is a basic human right which he is being deprived of.

The law, Government, society has forgotten vulnerable people like my brother and I would like to call upon them to reassess this as a matter of urgency.

Sharon McConnell

What might help

See our legal FAQs about visiting care homes: https://bit.ly/2I1hg8k

If you do not have internet access and / or would like a free printed copy, call: 01634 838739.

Activity ideas for children or adults with severe learning disabilities

Being at home at this time will no doubt be difficult for family carers, especially when you have a relative who has a severe learning disability who is unable to understand the reasons behind the restrictions. This extract of the 'Activity Ideas for Children or Adults with Severe Learning Disabilities: Part 1' information sheet can help you to think about what activities you could do to fill the time, keep your loved ones occupied and help to maintain a calm, happy household. Everyone is different and not all activity suggestions will be appropriate for every family. You are the expert in your relative so use ideas that you think will suit your family.

Remember:

- Some days will be better than others
- Your relative may have a very short attention span (but it may be longer if the activity is enjoyable and meaningful)
- It might be a time to try new activities

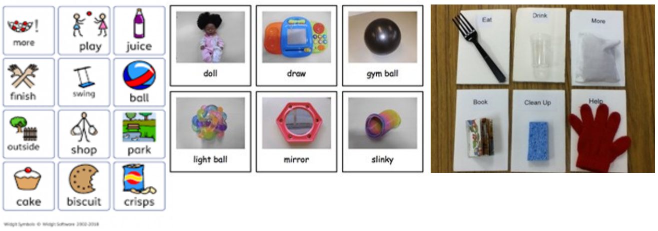
Setting a routine

Creating some kind of daily routine that provides predictability and structure can help to reduce feelings of anxiety that your relative may be experiencing. If your relative relies upon a structured week/activity plan or predictable routine, it could be really helpful for you and your relative to plan your day and build a new routine together. Build in a variety of activities each day, rather than just focussing on one type. You could try to ‘replicate’ (as far as possible) the activities that your relative does normally. For example: If they go trampolining or do activities such as bouncing, running, or swimming, think creatively about how you could replicate this - for example with water play, if you have a garden, or energetic or bouncy dance routines.

Using visual aids

Visual aids can be helpful in providing further clear structure and predictable routine for your relative, so they can see what is going to happen. They may help to reduce feelings of anxiety for your relative. They are also a great way of encouraging choice making and teaching about different categories of things e.g. food, activities, objects. Print or draw images and put them on the daily plan or timetable. If you don’t have a printer but do have a tablet or iPad you can create a digital visual timetable. You can also create a simple visual to look at what is happening, ‘Now and Next’:

Choose the kind of visuals that your relative already uses or images that they will understand. Some people use: Widget symbols, photos or objects of reference.



For those without a printer, cutting relevant images out of catalogues or magazines could also be very helpful. Also, use things you have photos of, or use images from, for example, cereal boxes.

If creating your own images, it is helpful to use simple picture/photo/symbol e.g. for a bowl – just a bowl - not a bowl surrounded by other things on a table, as this can be really confusing and distracting from what the picture is meant to represent.

Activity ideas for children or adults with severe learning disabilities - continued

Sensory activities

Some sensory activities can be made without you having to spend any extra money or at very little cost, here are some ideas:

- Watch a sensory story from YouTube
- Try a 'Story Massage' – this can be done with children or adults
- A scented bath with bubbles
- Finger painting - prepare for a lot of mess but also some great fun!
- Use a foot spa - try a bowl of warm water with oils or bubble bath if you don't have an electronic spa.
- Touching and sorting - Put some pasta, dried beans, lentils or rice into a big plastic bowl. Place this bowl and three empty smaller bowls on the floor. Let your relative dig into the big bowl and separate the mix into the smaller bowls.
- Live sensory events are being held on Facebook for those who have it.
- Messy play - make sludge by mixing cornflour with water in a bowl, until it looks and feels like custard, then run your hands through it!
- Make your own playdough:

    1. Mix 8 tbsp plain flour and 2 tbsp table salt in a large bowl.
    2. In a separate bowl mix together 60ml warm water, a few drops of food colouring and 1 tbsp vegetable oil.
       Pour the coloured water into the flour mix and bring together with a spoon.
    3. Dust a work surface with a little flour and turn out the dough.
       Knead together for a few minutes to form a smooth, pliable dough. If you want a more intense colour you can work in a few extra drops of food colouring.
    4. Store in a plastic sandwich bag (squeeze out the air) in the fridge to keep it fresh.

Art and craft ideas

- Make collages out of magazines
- Make a rainbow and put it in your window to show support for your local community
- Cut pictures out of paper or magazine/ catalogue to make a free matching/snap game – this can also help with labelling and communicating
- Make some cards or postcards that can be sent to relatives you are unable to see at the moment

You could also create a wall of handmade posters:

- Clear some space on a wall in the house
- Find a large piece of white paper (or old rolls of wallpaper, using the non-patterned side!)
- Collect different materials you can use
- Use water colours, pasta to stick on, other papers in different size, buttons, paper plates, old bottle caps, toilet paper rolls
- Be creative and use these materials to create beautiful posters, filling the wall space
- Put up to 3 different materials in front of the person and help them choose and place whatever they like on the paper
- Stay close so you can help the person to stick the different materials on the paper
- Try this activity at the same time everyday, creating a new routine, and encouraging the person to be creative!

Important note: some activities will be unsuitable for people who display Pica behaviour (eating inedible objects) and will need to be amended. For more information see the CBF information Pica behaviour sheet https://bit.ly/3eI6U90 or contact the Family Support Service (see page 5 of this newsletter).

Carer Catch-ups

Our new informal and friendly online catch ups are hosted fortnightly on Zoom by CBF family carer local champions. They last between an hour and an hour and a half, and family carers can join by emailing the host of the meeting that suits them best. They are designed as informal get togethers for family carers to ‘meet up’ with other carers who are experiencing similar issues.

Mondays at 11:30am
with Emma
(16th November and then fortnightly)
Carerscatchup6@thecbf.org.uk

Wednesdays at 7:30pm
with Balwinder
(18th November and then fortnightly)
Carerscatchup6@thecbf.org.uk

Wednesdays at 10:30am
with Diana and Lorna
(25th November and then fortnightly)
Carerscatchup6@thecbf.org.uk

Carer Catch-ups are informal chat groups with other families.

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

Celebrate successes, share tips, have a moan with others who ‘get it’.

Join our email network to find out more:
https://bit.ly/cbfnetwork

Meet our Carers Catch Up Host, Emma

When I was asked to be a host for the CBF Carers Catch Ups I was happy to say yes.

My son is 23 now and along the way I have learned so much. Much of the knowledge has come from other parents and carers who have found something which has worked for them or a way of approaching something which meant they got what was needed.

Chatting to other carers really helps me to continue to learn and get ideas about things we may be able to do for my son.

Something one of the ladies said after the Catch Up was that it made her feel like she was not such a bad Mum after all. I think that coming along to the Catch Ups for this reason alone, is worthwhile as we all need to give ourselves a break and remember we too, are human.

Carers Catch Ups are a social chat over zoom with no judgement and bags of understanding and practical suggestions from others who have maybe struggled or are struggling in similar ways. It is a great place to vent frustrations and to share good news too.

You will be listened to.

Its easy to join, just find a Catch Up which suits you and sign up.

Emma

Carers Catch Up Host

Covid-19 Frequently Asked Questions Answered by the Legal Panel

The legal panel is made up of a number of law firms and barristers specialising in learning disability, enabling a co-ordinated approach to emerging issues. The panel is well placed to identify strategic legal issues and cases that will have the greatest impact, and is part of a wider approach to getting the right level of legal support for families at the right time (e.g. utilising template letters and other resources as appropriate to ensure early resolution to legal issues).

Since March 2020, legal panel members have been considering questions families have raised with us related to the coronavirus pandemic. We have included a selection of questions and answers below but more can be found on our website here: https://bit.ly/3axtIov

If you would like a paper copy of the FAQs please get in touch via info@thecbf.org.uk or 01634 838739.

Please note - as government guidance continues to be updated and restrictions vary across the country the legal panel are working hard to keep answers up to date. For the most recent versions please see our website.

With very grateful thanks to the lawyers, barristers, and others who have generously provided their time and expertise to produce these FAQ resources.

Q: Are people in single person supported living services now able to form a bubble with another household? This is really important to many families and could mean they can now visit their relative without social distancing.

A: The current guidance is here: https://www.gov.uk/guidance/making-a-support-bubble-with-another-household

Essentially any single person in supported living services is allowed to form a support bubble, but the guidance is different for those with live in carers as opposed to those who have carers visit.

If you have live in carers you can only form a support bubble with a household consisting of one adult. If your carers come to visit you, you can form a support bubble with another household of any size.

Depending on the nature of the supported living this might be a difficult distinction to make, however it is arguable that given the importance of family visits a generous interpretation should be given and those for example who have carers live on site but not within their home should be allowed to form a support bubble with a household of any size.

Covid-19 Frequently Asked Questions - continued

Q: Schools are asking families to sign waivers when they go back in regard to their safety and support in the school setting. This is said by the Department for Education to be illegal, but what is the best approach for families to take when this happens to them?

A: Schools should not be asking families to sign waivers and parents should decline to do so when asked. A decision that a child cannot attend school because their parents have not signed a waiver is likely to be considered an unlawful exclusion. Where schools are insisting on waivers, we suggest that families report their concerns directly to the DFE and ask them to take steps directly. Where this is impacting on the child's education and cannot be resolved through discussion, legal advice should be sought.

Q: I'm keeping in contact with my son with learning disabilities who lives in his own home supported by staff, by visiting weekly standing in the garden maintaining the two-metre separation. However, I am concerned that the police will question this as I am over 70 and classed as higher risk. Does the needs of the relative, who needs reassurance trump the age-related

A: During the height of the pandemic, individuals classed as 'clinically extremely vulnerable' to complications from COVID-19 were advised to take extra precautions in order to avoid infection. This is known as 'shielding'. Individuals at higher clinical risk received a letter from a medical professional advising them to stay at home. This was advice only and was not enforced by the police.

Since 1 August 2020 shielding has been paused in England, this means that clinically extremely vulnerable individuals are no longer being advised to stay at home. There are therefore no restrictions on you visiting your son in the way that you describe, unless you are living in an area that is subject to a local 'lockdown'.

The list of areas that are currently subject to local restrictions is available here: https://www.gov.uk/government/collections/local-restrictions-areas-with-an-outbreak-of-coronavirus-covid-19

If you are currently living in an area that is subject to a local or national lockdown you are not permitted to visit your son, including in his garden, unless you are part of a support bubble. Guidance on support bubbles is available here: https://www.gov.uk/guidance/making-a-support-bubble-with-another-household

Your questions from the email network

Our son is living on his own in his own home with 24/7 support. We should now be able to see him in his garden (rather than through the window!). However, I am quite sure that, even with his support worker with him, it will be difficult to get him to stay 2m away from us. Normally when we meet I always have a hug and a kiss (have been having on screen/through the window kisses since the beginning of lockdown!) and dad gets a hand-shake – a bit harder to achieve virtually!

Has anyone got any ideas/experience of how to meet up safely with their adult son/daughter?

For a long time our son's Care Provider said we couldn't even meet up outside as he was not allowed to have physical contact with us.

They have now agreed that we can meet.

Here is what we did to achieve this change of heart:

- **We rang his GP, his Psychiatrist and a LD nurse who knows him.**
- **We asked what they felt the risk of getting the virus from us was in an outside environment weighed against the risk to his emotional well being of not seeing us.**
- **They all supported us and said the risk was extremely low and the GP agreed to speak to the Manager of the home.**

My daughter, SLD and Autistic, shares a cottage with one other so we have had to wait until after 4th July because we can't be a bubble. We are having her home a few days later giving a couple of days to risk assess her favourite places and there will be cuddles.

You have to do what's best even if it means waiting a few more days. I 'm spring cleaning her bedroom so everything is perfect, so excited.

Surely there is an exemption in the regulations for disabled people?!

Want to ask your own questions or share your experience?

Join the Family Carer Email Network at: bit.ly/CBFFEN

We also have an email network for professionals, find out more and apply at: https://bit.ly/CBFPEN

Since writing this we have been allowed to visit our son in the garden and have done this twice. The Provider has agreed "reasonable adjustments" so we can have a quick kiss/hug/handshake providing we all – our son included:

Wash our hands before visit
Wear masks and gloves
Clean all surfaces we touched
Put all our clothes in the linen basket
Use gel on our hands when we arrive
Dispose of these properly afterwards
Have shower or bath after the visit.
Leave for 72 hrs before washing.

Workshops and training

The pandemic brought a swift and sudden halt to all our workshops and we had to cancel many planned events – some already half delivered. As time went on, we could not see an end to the strict controls on meeting in groups in public places, but we could see that our workshops were still needed and could offer good support to families. We decided to re-work our workshop materials so that we could offer the same experience but via an online platform. We gathered as many of our co-trainers as we could to have a discussion about the best way forward and as usual, they came up trumps. Importantly, they were all behind the idea of going digital and using this new platform to deliver our workshops. We were able to redraft our content, design a system that would enable us to test it out in practice before going 'live'.

A big hurdle was deciding which platform we would use to host the event – eventually we opted for Zoom: this was the simplest and easiest to use and did not require specialist knowledge or special equipment to join a session. We held our first online event mid-September and Jonathan, CBF Workshop coordinator, was pleased (and relieved) to report that it went without a hitch. We were able to learn a great deal from the first experience – make sure everyone is back after a break and their camera is on being one – and able to share with all our trainers. We shall certainly be offering this blended approach – face to face and online – to any future workshops we deliver. As ever, we are indebted to the hard work and commitment from all of our trainers.

And watch out for our new PICA workshops – coming to a venue near you from early 2021!

We are now able to offer all our workshops as online events, so do please contact us for further information (email: workshops@thecbf.org.uk). This means we can extend our workshops to isolated and hard to reach families and locations as we work to be more flexible about delivery. Details of the workshops we offer are here (https://bit.ly/35itX7w) or ring 01634 838739 to discuss individual requirements.

About our workshops: *"Brilliant workshop – I have learnt so much"*

FRONT LINE FAMILIES

Thanks to the emergency Covid-19 funding distributed via DHSC, the Challenging Behaviour Foundation has been able to work in collaboration with Bringing us Together and Newbold Hope to provide additional support to between 200-400 families since August 2020.

Support has included webinars for families of children with special educational needs and disabilities whose behaviour challenges and Zoom Room chats for families of individuals with learning disabilities or autism whose relatives are living away from home. This collaboration means we are able to signpost families to each other's support, for example CBF Behaviour Chats or Carer Chats, so that families can benefit from as many forms of support as possible during this isolating time.

It also means that we can share feedback from families participating in all programmes to the Government and NHS England so they are hearing directly from families who really are the frontline of support during this pandemic.

Our small scale evaluation has found that the Frontline Families programmes have helped to:

- reduce feelings of isolation and helplessness,
- establish a community of peers,
- offer much needed support and advice at a time when families have felt as though they are on their own.

One family carer said: ***"It feels like being a little boat out alone out at sea, then seeing lots of other boats with their lights on"***

We hope to be able to secure more funding to continue this work. Keep an eye on our webpage here: https://bit.ly/FrontlineFamilies

Thank you

Virgin London Marathon

For 2020 the CBF managed to get a coveted charity place for the London Marathon which was due to be held in April. As with lots of other events it was cancelled but runners were given the chance to run a marathon distance near their homes on 4th October. Ben Matthews won the ballot for the CBF charity place and ran the virtual London Marathon along part of the North Downs Way, braving the rain, and raised an amazing £2715.25 (including Gift Aid).

Thank you for all your hard work Ben and for all those who supported him!

Donations

A big thank you to all those who support us with regular and one off donations through Virgin Money Giving, Donr and direct debits through our bank.

If you would like to donate but do not have internet access, please give us a call on: 01634 838739 for details.

Also thank you to those taking advantage of fundraising for free, by using Amazon Smile, Everyclick, Give as you Live and Easy Fundraising when doing their online shopping. It really does make a difference and we're grateful for your support.

In memoriam

Sometimes we receive donations from people whose relatives have passed away. We have received donations from Melinda Battersby in memory of her mum. We send condolences to the family and thanks for their kind donations.

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.

Why not purchase a number, or two, as a Christmas gift for friends and family?

To sign up please email: info@thecbf.org.uk

Support and funding

During this pandemic it is more important than ever to support each other and we encourage family and friends to keep in touch remotely. Our family carer network (see page 14) is still operating and we hope that connecting by email to people in similar situations might provide you with some additional comfort, advice and support, as well as talking to people in our new carer catch ups (see page 11). Our family support line is still open 5 days a week to support families. We are continually producing new resources and following the latest guidance to inform families.

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/support-us/support-us.html

If you would like to help us in continuing to support families during this time please consider donating: **Text CBF to 70450 to Donate £3.** To donate more simply text CBF followed by the amount you wish to donate. i.e. CBF 10 to donate £10.

Thank you to the funding, distributed by Department of Health and Social Care as part of the Government's £750m charity package, which enabled us to send out printed copies of our newsletters to family carers. It is important that we provide a range of accessible information and support in different formats for families during this difficult time.