

Support during this pandemic

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

What's in this Newsletter?

These are difficult times for everyone - and the challenges are magnified for families with relatives with severe learning disabilities whose behaviour challenges. Whether your relative is living in the family home, residential care or supported living, there are worries and challenges to overcome. Although my son no longer lives with me, I am a big part of his life and his routines, and I have many sleepless nights worrying about him. Families who are supporting their relatives at home often have greater challenges with no respite, juggling the needs of different family members.

We understand the range and diversity of these challenges and the need for practical information and support for families. There are particular challenges for families whose relatives are in inpatient units, or whose relatives are a long way away from them and who cannot use the internet to keep connected. This newsletter has been produced as a printed copy to summarise and share the information, guidance and resources produced by CBF and others, and to get it out to people who do not have access to the internet or social media, and who may be feeling isolated and forgotten.



Vivien Cooper
Family carer and
CEO of the CBF

Our small CBF staff team are all working from home at the moment - our helpline is still open, alongside our email networks and casework support. We have uploaded some of our DVDs onto our website so they are available to anyone who needs them, and we have developed new practical resources to help in the current lockdown, with more being written. Alongside this we are working to influence policy to address the difficulties we know families are facing and encouraging officials to recognise and support family carers in their vital role. Mindful that not everyone has internet access, we have produced this paper newsletter, and have included details about getting in touch by phone where we can. Please get in touch if there is anything we can help you with.

Resources in this newsletter

Included in this newsletter are sections from our information sheets.

Page 6: **Spitting information sheet**, we know there are concerns about how this will be perceived by the public and health care staff.

Pages 7-10: **Challenging Behaviour visual summary** which covers how to be prepared, what to do if you see a change in behaviour and if the behaviour becomes challenging, and what to do after an incident.

Pages 11-12: **Information cards for going out**, to help explain to the public and police about your situation.

Page 13: **Activity ideas** and **keeping healthy**, we understand that social isolation is challenging and finding activities your relative enjoys can help.

Page 14: Some practical ideas on **handwashing** and games.

Page 15: **Top tips** from other families.

If you do not have access to the internet you can give us a call on: 0300 666 0126 and our family support team will be able to provide information and support or simply be a listening ear.

To read this and previous newsletters online visit:
<http://bit.ly/CBFNewsletters>

Online resources

If you can get access to the internet our website has multiple pages dedicated to providing useful information during this crisis.

Information and resources: <https://bit.ly/CV19info>

We have produced new resources specific to the current situation, free to download.

Government and NHSE Guidance: <https://bit.ly/NHSECBF>

We have collated information provided by the Government and NHSE.

Covid 19 & learning disability news: <http://bit.ly/NewsCV19>

Regular updates about guidance, work the CBF is doing to influence the Government and NHSE.

Resources from other organisations: <https://bit.ly/ExtCV19>

Other organisations are also producing helpful resources for families this page collates them.

Videos with practical help: <https://bit.ly/VideosCBF>

We have uploaded our DVDs to our website so everyone can watch them for free.

Parent Carer Wellbeing and Self-Isolation

Jo Griffin is a family carer and is currently conducting Doctoral research into parent carer wellbeing. Jo is also a member of the Tizard/CBF Family Carer Research Alliance. Below, Jo shares some top tips for how you can look after your wellbeing during this difficult time, drawing on her experiences as a family carer and researcher. Jo has also written a blog which expands on the topics covered in this article including a simple breathing exercise to help with relaxation which you can read here:

<http://www.affinityhub.uk/blog/>

During these uncertain times some of the experiences that we, as Parent Carers, are going through are particularly unique. Hard-won services and support may diminish or disappear. If your child does not live with you then restrictions on seeing them may be very difficult.

Parent carers can also be resolute and resourceful because we've learnt we have to be. These skills may help us now.

Know what you need to and accept what you can't

Uncertainty adds to our sense of anxiety and hopefully guidance and information from sources such as the CBF help clarify your rights and those of your family members.

However, there is much we can't foresee about how the next few weeks will unfold. We know, probably more than most parents, that we can't predict the future. We have to learn to live with this uncertainty while recognising that this situation will change.

Routine that works for your family

Currently, there is a lot of information from schools, social media and other families about what we 'should' be doing at home. You know best what routines work in your household, and what will definitely not. Do what you can to make life easier and more comfortable for your family. A weekly routine (with visuals, if that helps your child) may provide structure as the days can start to merge into one. Include your own needs in that routine.

Take time for you

You need this. Even if it's ten minutes peace and quiet on your own with a cup of tea, time spent speaking to a friend or watching your favourite programme on TV. It may involve you saying 'no' to other (less important) demands on your time.

Manage Stress

How you do this will be personal to you. Activities like mindfulness, breathing techniques, music, reading, colouring in books or apps and gratitude exercises can all help (see link at bottom). Being out in fresh air, sunlight and nature is well documented as a mood-enhancer (while sticking to the 2 metre rule). Even if you can't get out sit near a window to make the most of the natural light throughout the day.

Don't forget the basics

We all know the important things: eat healthily, drink plenty of water, get enough sleep and exercise. Yet sometimes we forget to do them. It can be hard to maintain them as an everyday priority but they are vital – every day.

The Right kind of connection

We need to stay socially connected despite physically distancing. But quality is more important than quantity. It may be that one good conversation will be worth more to your wellbeing than scouring social media for hours. If your child is living away then finding ways to communicate – online, sending videos or photos or getting updates from their key worker may help you feel connected.

Little wins

Remember to recognise what you've achieved each day, however small. It's natural for human beings to focus more on the negatives of the day so it takes practice and conscious effort to re-focus on the positives. We are living in extraordinary times which require kindness to ourselves, our loved ones and our community.

For more information on looking after your wellbeing and useful links please visit www.affinityhub.uk/6/wellbeing

Joanna Griffin

Parent Carer and Counselling Psychologist



Mindfulness during Lockdown

Mindfulness has been demonstrated to be a useful technique for reducing stress and anxiety. Mindfulness practice typically starts with being still, eyes closed and choosing to bring awareness to what we are experiencing at that moment. This may be physical sensations in our body, e.g. the pressure of our feet against the floor or noticing how the air enters and leaves our body as we breathe or a throbbing ache in the shoulders. It is inevitable that we will become distracted; drifting off into our thoughts or by things going on around us. It can be like trying to hold onto a bar of slippery soap. This is often the point that people give up and think mindfulness is not for them.

BUT if you are willing to continue, you take an important step to becoming more mindful. Every time you are distracted and you notice that you have been distracted, you wake up. You break the chain of mind wandering and mindless reaction from distraction to distraction. You create the opportunity to refocus your awareness back to that chosen physical sensation. In doing so, you strengthen your ability to be more present and more aware of what is happening in your life moment by moment. It is like you strengthening your mindfulness muscles.

“Like any exercise, it needs to be practiced.”

Choosing to take a few minutes each day when you can purposefully choose to bring your awareness to your breath can be an effective way of bringing mindfulness to your life.

Choosing to pay attention is one part of being mindful. The other part is how we start to notice how we talk to ourselves during practice. For example, how easy it is to form judgments about ourselves, such as “I’m no good at this,” or “This is too hard.” To be mindful is to choose to pay attention without this judgement. This isn’t easy but the more you practise the more you start to get better at describing how your mind works and just how often you notice that it can be negative.

This doesn’t mean there is anything wrong with you. People are surprised when they speak openly with others about how they think about themselves. It is the norm to be our own worst critic, to judge our self negatively, to think we are not quite as good as we should be.

Learning to be mindful is to discover that we can choose not to buy in to our negative thoughts and start to realise that our internal mind chatter is like a radio that is on all the time. We can’t actually switch it off, but we can choose whether to listen to it or not. Over time we can learn to disentangle ourselves from the barrage of negative comments that occur in our head. In this way we can start to act in a kinder way towards ourselves.

Steve Noone

Clinical Psychologist and Senior Lecturer

Temporary changes to the children and young people with severe learning disabilities legislation

The Coronavirus Act passed by Parliament allows the Government to make temporary changes to existing legislation. Two significant changes to the legal framework for children have now been made which are likely to have an impact on children with severe learning disabilities and their families.

The **Education, Health and Care Plan (EHCP) legislation** has been amended until the end of June 2020 (with potential to extend beyond this date).

- Previously, local authorities had a duty to provide education and healthcare specified in an EHC plan. The amendment removes this duty and asks local authorities to use ‘reasonable endeavours’ to secure the specified provision.
- Timescales relating to EHC assessment and plans have also been relaxed, so they can be completed “as soon as reasonably practicable.”

- Local authorities should keep a record of any changes, contact the family carers or the young person and explain why the changes are happening and how they will be applied.

Children’s Social Care legislation has been amended until 25 September 2020 (with potential to extend beyond this date).

- This amendment has removed some of the duties relating to children in care, including 6-weekly social worker visits (which can now be via phone call) and independent reviews.
- Children’s homes are not required to have twice-yearly Ofsted inspections or monthly independent visits and the care standards governing quality of care have been amended so that staff must have the right skills and qualifications where “reasonably practicable.”
- Care planning safeguards related to short breaks will no longer apply after a child has spent 17 days in a single short break; they will only apply after 75 days of short breaks within one year.
- Children’s homes could previously only deprive children of their liberty if they had a court order but can now do so temporarily under the Coronavirus legislation if a child has suspected Covid-19, in order to prevent the spread of the virus.

Care Act Easements: one more step towards degradation of legal duties of care for people with learning disabilities

Amongst other measures to mitigate against the devastation of COVID-19 pandemic, [The Coronavirus Act 2020](#) (COVID Act) has relaxed aspects of the Care Act 2014 (CA 2014). These 'easements' came into force on 31 March 2020, with accompanied [Guidance](#) that sets out how Local Authorities (LAs) can 'temporarily' relax their duties 'in extremis'. 'In extremis' is defined as when a LA is unable to comply with their CA 2014 duties due to a significant increase in demand on social care or a significantly depleted workforce (s6 Guidance). As of 27th May five local authorities have already [triggered the Care Act easements](#). It will be surprising if many other LAs were not to follow.

“The Guidance states LAs must evidence their decision and communicate this in an accessible format to all providers, service users and carers.”

Yet many families report that they have [not sufficiently been made aware](#) of changes in service provision.

The easements allow LAs to 'prioritise' those in most need. The impact of this is potentially catastrophic for people with learning disabilities and their families. Although having to maintain 'duties in the Care Act 2014 to promote wellbeing', LAs can choose whether or not to carry out needs assessments, follow the CA 2014 eligibility criteria, assess people for financial resources, develop care and support or care plans, meet care and support needs, or give effect to a preferred place of accommodation - unless a failure to do so would result in a human rights breach. Such rights under the European Convention of Human Rights include: the right to life (Article 2); the right to freedom from torture and inhuman or degrading treatment (Article 3); the right to liberty and security (Article 5) and the right for respect for private and family life (Article 8).

LAs have been told 'methods of prioritisation will be unique to each area'. Guidance (Annex B) states 'local areas may choose to agree a minimum standard that Local Authorities and care providers would work towards and which reflects their local situation'. So for example, continuing to support a person to manage their toilet needs would be classed as a priority (removing this support would breach the person's dignity under Article 3).

Reducing or removing staff hours to support another person to make themselves a nutritious meal, however, may not be a priority. Whilst this appears a sensible way to prioritise need where resources are tight, the person who loses support to make meals may start to eat poorly, one mother stating:

“He is putting on weight, but as he doesn't have access to much money he can't buy much without staff – he is still going to the little shop at the end of the road to buy a few things by himself, doesn't understand that lockdown applies there too!”

Care workers are often the main source of social contact for people with learning disabilities. They are therefore at additional risk of social isolation and loneliness. This could exacerbate clinical depression, challenging behaviour and self-injurious behaviour (see <https://bit.ly/2yjpSSB>)

Liz Rolfs, Chair of New Forest Mencap states:

“Several older parents have preferred to have their loved one back home with them. Others have actually been asked by the service provider if they would take their son or daughter home as their ability to support them was threatened (staff shortages due to COVID in the main). Families are busy trying to keep a routine going and devising activities for their son or daughter. How long can this be maintained?”

Due to expire after 2 years (s89), the COVID Act can be extended for 6 months at a time (s90), so unless challenged, the repercussions of the easements for people with a learning disability and their families could be felt well beyond the pandemic.



Professor Rachel Forrester-Jones

Director of the Centre for the Analysis of Social Policy (CASP)

To find relevant guidance, including the Care Act 2014, please go to <https://bit.ly/NHSECBF>

Find information about challenging behaviour for family carers on the CBF website here <https://bit.ly/CBFAllRes>

If you do not have internet access and would like more information about the Care Act easements, please contact our family support team on 0300 666 0126 .

We and other charities, individuals and groups will continue to champion and uphold the rights of our group and have already had successes in influencing government.

Centre for
the Analysis of
Social Policy (CASP)



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Your Questions From the Email Network



The Family Carers' Email Network enables you to be in touch with a number of families around the UK. You can share experiences, information and receive support - without any obligation to reply or to identify yourself. Examples of recent conversations include:

Hi Everyone

How is everyone doing during this nightmare situation?

Is anyone still managing to get visits or contact face to face to their loved ones in a care home or supported living?

It is so hard for people to understand why family are not allowed to see them.

Would love to hear how people are coping.

Worried parent

We have our 25 year old autistic, non verbal son at home. Day centre and respite shut so he presently thinks its holiday time. McDonalds shutting was a blow too! Trying to get him out for a walk every day but he gets frustrated as we don't actually end up anywhere. Good luck everyone! I think us parents have been forgotten about. Stay safe x

I am torn between pushing to be able to visit her (perhaps using my H&W deputyship order) and worrying about putting her at risk.

My son doesn't communicate much with speech or understand much language. However, we have been Skyping or Facetiming him and he really enjoys it! We get lots of smiles and he even kisses me on screen and shakes his dad's hand! I think it helps him to know we are still there. It is good for his staff team too. So I would encourage you to try video calling even if your son/daughter cannot communicate.

My girls have seen a big reduction in support. I am obviously picking up the slack, going to bed very weary when this is over, whenever that may be. Stay safe.

The provider (who I employ) and I decided that if he became ill, I'd wear PPE just like the staff, and look after him. Two staff have already become absent, so staff are relying on me. It's not in black and white, as it has to be safe for the person, who needs care regardless of the virus.

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



We also have FAQs from families answered by our Legal Panel, this includes information about maintaining family contact: <https://bit.ly/FAQCBF>

If you do not have internet access contact family support for more information: 0300 666 0126

The care home have set up on site activities and are blessed with large expansive grounds so our son runs circuits with staff and housemates to help him burn off his abundance of energy. We got some lovely photos of him today doing yoga on the Youtube channel with staff and a housemate. We have just bought him a Smart TV for Youtube in his own room and he has a Spotify account as he enjoys music. We are trying a Zoom video call for the first time this evening, we hope this goes some way to reassure him and allay our worries.

My son is non-verbal. So I cannot do Skype or FaceTime etc with him. I have to phone the support worker to ask whether my son is Ok etc. He is not allowed to go out in the car as there should be social distancing in the car too. There are two workers with him in the car. Poor thing. No drive in the car and no visits from Dad and Mum. I think with time my son will realise that we are not coming and he will have some behaviour.

You're so right no contact is tough, the manager of my daughters home called me today to let me know how's she's doing. She's ok with not going out, she lives in a group of cottages with grounds, enjoying the site. This might make a new norm, not always wanting to go shopping.

My relative is in 52 week placement and is coming home as usual this weekend. This is in agreement with all team involved in care as disruption and consequent behavioural distress by changing such long established routine likely to lead to real difficulties with care. Family are following all government directives currently and will collect from outside care service and return the same.

We decided to bring him home, we thought that was the safest option. My son could not self isolate if he became infected. I appreciate we are fortunate my Husband is retired and I am semi retired. We will struggle, will have to see how it goes.

I was concerned about no contact as he is home every 10 days for weekend, we have set up FaceTime. He can hear me, I copy his sounds and he seems to enjoy listening to me. It takes about ten minutes before he recognises my voice. Done this three times so far, last time he actually moved closer to iPad, which was great.

Want to ask your own questions or share your experience? Join the Family Carer Email Network at: bit.ly/CBFFEN

www.challengingbehaviour.org.uk | 01634 838739 | The Old Courthouse, New Road Avenue, Chatham, Kent, ME46BE

Spitting

Many families report that their relative displays spitting behaviour, and with the pandemic this behaviour can cause even more problems than usual. We worked with a clinical psychologist to produce an information sheet for families— excerpts are re-produced here.

Why Might People Spit?

There are two main types of spitting: spitting saliva and spitting phlegm. Leaving aside specific medical conditions, there's no physical reason why most of us need to spit saliva. Most of us were taught that it's unhealthy to swallow phlegm. So, if your family member is spitting in a way that's socially unacceptable, the first thing to decide is: Is it saliva or is it phlegm?

If it's saliva:

- 1) Does s/he have a medical condition that means that s/he produces too much saliva?
- 2) If not, do you think that s/he's doing it 'on purpose'? For the person doing the spitting, spitting saliva on purpose has several advantages:
 - 1) It's quite easy for most people to produce enough saliva for spitting;
 - 2) Saliva doesn't taste nasty;
 - 3) Spitting saliva can be done again and again without hurting the person or tiring them out;
 - 4) Spitting saliva onto one's chin or fingers can feel quite nice to some people.

If the person's spitting phlegm:

- 1) Does s/he have a (short-term or long-term) medical condition to account for this?
- 2) If not, do you think that s/he's doing it 'on purpose'? Spitting phlegm isn't usually as easy or 'convenient' (for the person doing the spitting) as spitting saliva. However, it may have more of an impact if the person's doing it on purpose, as many people dislike someone spitting phlegm more than saliva.

What to Do About It?

If you think that there may be a medical reason why your relative's producing (too much) saliva or phlegm, seek medical advice about how to reduce it. If this is the case, unless/until the excess saliva or phlegm can be reduced or eliminated by medical reasons, see if you can get your family member to spit into a disposable tissue.

However, what if you think that your family member's spitting 'on purpose'? There are several possible general reasons why someone with a learning disability might spit on purpose:

- 1) To get your attention;
- 2) To avoid doing an activity;
- 3) To end an activity;
- 4) To amuse themselves (if they tend to play with the saliva or phlegm after they've spat);
- 5) To annoy you!

The spitting may be 'multifunctional': it's used for different reasons (possibly all of the above reasons) at different times.

So, ask yourself these questions:

- 1) When does the spitting happen most often?
- 2) When does it happen least often?
- 3) Where does it happen most and least often?
- 4) With whom does it happen most and least?
- 5) Does it happen more or less when the person's doing certain activities?
- 6) Does it happen more or less when the person's left by him/herself?
- 7) How do you (and other people) react when the person's spitting?

Paying attention to these questions over the course of a week or so hopefully will start to give you some clues as to why your family member's spitting.

Then, you can think about how best to respond:

- 1) If they're doing it to get your attention, find an alternative way for them to get your attention. Remember: this new way must be quick and convenient, or the person simply won't bother. Shouting or screaming may not be ideal but they're better than spitting!
- 2) If they're doing it to avoid doing an activity or to end an activity, give them another way to signal that they don't want to do the activity or that they want it to end. Ideally, see if you can shorten activities or make them less unpleasant for your family member. In any case, you need to 'listen' to the alternative methods that you're giving your family member.
- 3) If you think they're doing it to amuse themselves, give them other similar activities (ideally water play) instead.
- 4) If you think they're doing it to annoy you, give them as little attention as possible when they spit. Don't bother 'telling them off': if you've read this far then the spitting's been going on too long to be affected by you telling them off! However, do immediately praise and cuddle them as soon as they've stopped spitting and started approaching you in a more acceptable manner.

Ignoring spitting that's been going on for a long time is unlikely to work and may make things worse. So, instead, pay the spitting as little attention as possible, whilst giving your relative lots of attention and praise for more appropriate ways of behaving – even shouting and screaming!

Many people feel very stressed by their family member's spitting. That's okay – and it's also okay to feel disgusted by it. We don't like to see people spitting because spitting has in the past been a way that deadly diseases have spread. You may want to 'let off steam' to someone (such as the CBF helpline), so that you can put those feelings to one side when you're with your family member.



Supporting Children and Adults with Severe Learning Disabilities at Home during the Coronavirus Pandemic

We know that the pandemic restrictions have disrupted routines and this may lead to an increase in challenging behaviour. We have put together a practical resource to help with this, and this is reproduced on the following 4 pages. Copies are available online here: <https://bit.ly/CBFCVS> to download or share.

BE PREPARED



Make sure plans are up to date and followed

POSITIVE BEHAVIOUR
SUPPORT PLAN

COMMUNICATION
PASSPORT



Add a new routine with familiar and favourite activities



Use visual timetables to communicate the routine

EXAMPLE



Provide choice



Reduce demands your relative finds difficult



Praise and reward positive behaviour



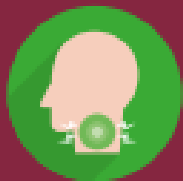
Involve your relative in everyday activities



Remind your relative of rules

IF YOU SEE A CHANGE IN BEHAVIOUR

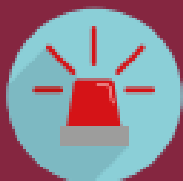
CHECK:



Physical health



The environment



Triggers which you know affect your relative

TRY TO WORK OUT WHAT YOUR RELATIVE IS “SAYING” THROUGH THEIR BEHAVIOUR. DO THEY...



Need positive attention?



Need something tangible?



To avoid or escape something?



Feel uncomfortable for sensory reasons?

INFO SHEETS

IF YOUR RELATIVE'S BEHAVIOUR BECOMES CHALLENGING

TRY THE FOLLOWING:



Stay as calm as possible, use low voice and relaxed body language



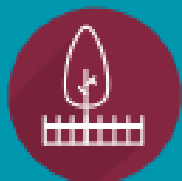
Divert or distract



Give your relative what they are asking for if possible



Keep language simple



Give your relative some space and time if it is safe to do so



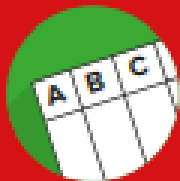
Use body signs and gestures



The Challenging
Behaviour Foundation

FOLLOWING AN INCIDENT OF CHALLENGING BEHAVIOUR:

REVIEW WHAT HAPPENED AND WHAT YOU COULD CHANGE TO AVOID IT AGAIN:



Try to keep a record of what happened before, during and after



Keep a record each time and you will build up a picture



Ask for help from social worker, community learning disability team or behaviour support team

LOOK AFTER YOURSELF:



Take some deep breaths



Can someone else step in?



Can you have time out?



Can you discuss?

[READ MORE](#)



The Challenging
Behaviour Foundation

PLEASE DO NOT SHOUT AT ME!
Please be kind & respectful

I have a Severe Learning Disability

This means I can't understand lockdown.

- I can go out with more than 1 person as this keeps me safe.
- My support/carer helps me to keep 2 metres apart from anyone who is not my carer or a member of my household.

Government guidance says that, because I have a specific health condition that requires me to leave home to maintain my health, I can:

- go out for exercise 2 or 3 times a day if I need to
- travel beyond my local area to a quiet, open space to exercise

I have a care plan that confirms this

For more information search 'Government guidance coronavirus FAQs what you can and can't do'

To find out more about people who have severe learning disabilities, visit:
www.challengingbehaviour.org.uk



A4 Information sheet (previous page)

This could be used in a number of ways:

- To proactively inform your relative's neighbours that they will be going out and not following all social distancing guidance.
- To send to your local police station to inform them of your relative's rights.
- To share on social media to raise awareness in the general public and so fewer families are made to feel uncomfortable in their communities.

Information Cards

These can be cut out and with the front and back stuck together. Alternatively, take a picture on your phone to show people.

These are intended to be handed to anyone who asks why you are out and about. They contain all the information that the police or public need to understand why your relative is not following the social distancing guidance. We hope this will save you or your relative's support worker time explaining and allow you/them to focus on supporting your relative.

We hope that these resources will promote kindness and tolerance towards people with severe learning disabilities during what is already a very difficult time for them and their families.

PLEASE DO NOT SHOUT AT ME!
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I have a Severe Learning Disability

- This means I can't understand lockdown.
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The Government guidance updated on 8th April 2020 says that, because I have a specific health condition that requires me to leave the home to maintain my health I can:

- go out for exercise 2 or 3 times a day if I need to
 - travel beyond my local area to a quiet, open space to exercise
- I have a care plan from my Doctor/Social Worker that confirms this.

For more information here is the link to the Government guidance Coronavirus FAQ's 'What you can and can't do' – Question: 15
<https://www.gov.uk/government/publications/coronavirus-outbreak-faqs-what-you-can-and-cant-do/coronavirus-outbreak-faqs-what-you-can-and-cant-do>

To find out more about people who have severe learning disabilities, visit: www.challengingbehaviour.org.uk



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To find out more about people who have severe learning disabilities,



Activities

With the pandemic restrictions there have been disruptions to usual routines and activities, and more time is spent in one place. We have worked with families who have shared ideas about activities that can help and have developed an information sheet that describes things to do together. 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.

Fun activities

Create a memory book of activities you are doing at the moment. Print out photos, group them together and put them in scrap book. Talk about the groups of photos you are creating with your relative. Alternatively create albums on your tablet/ computer. Let your relative choose which ones to look at



Make a simple sorting game (or buy one). Find pictures (e.g. from magazines) or print some out, in themes. For example, farm is the theme and you print pictures of farm animals, tractors etc. You spread them out and use simple instructions like "Where are the pigs?", "Find the tractors" etc. Different themes can be used depending on the interests of your relative

Do some jigsaw puzzles together, you can also get free puzzles online





Pamper time – facial/face masks, painting nails, make up

Make homemade musical instruments from household objects – use these whilst playing your relative's favourite music

Take a trip down memory lane in the comfort of your home. Get out your family photos and re-live some happy times. Maybe filter out some of the photos of preferred activities that are not accessible at the moment, if it could cause your loved one to become anxious because they want an activity they won't be able to do. Look at family photos – use family photos to – show me, who is, where is, give me etc

Downtime

It is essential for you and your relative to have some down time during the day, maybe during the evening to help with preparing for going to bed. Activities that can help with relaxation can include listening to favourite music, watching TV or videos, having a hand or foot massage or a treat!

- Make the ordinary extra special by having a treat e.g. a luxury hot chocolate with cream and marshmallows. Get your relative to help if they would like to 
- If you have created a sensory space, use this as one of your calming, relaxing activities
- Settle down to watch a film together if your relative has a good concentration span and would enjoy this. Make it a special event by having popcorn. For those with a short concentration span, watch short clips of things they enjoy 
- Hand/foot/back massage
- Listening to relaxing music or sounds
- Online stories

Important note: some activities will be unsuitable for people who display Pica behaviour (eating inedible objects) and will need to be amended.

Keeping Healthy



As well as keeping the virus at bay, we also need to take care of our general mental and physical health. People with learning disabilities should still be accessing annual health checks even though they may be carried out differently, and if you are concerned about a health need you should contact your GP.

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.

Here are some tips to ensure that they get the best possible health care:

- 1) Update or create their hospital/health care passport - (Example hospital passport templates are available to download from Mencap, Include Me Too and our information and resources page).
- 2) Update or create a communication passport, examples of which you can find on our Covid 19 Information Page.

- 3) 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. e.g. what steps health staff need to take to successfully take blood/take blood pressure.
- 4) Make sure that any medication changes/allergies/adverse reactions to medication are recorded in the hospital/health passport.
- 5) 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.
- 6) Read our advice on 'Going into Hospital with COVID-19' on our website or contact family support.

We have worked with families to co-produce an information sheet on Learning Disability nurses which is enclosed with this newsletter or a copy can be found on our Covid 19 information page. Learning disability nurses can provide a range of support advice and information.

Handwashing

Government advice to stop the spread of coronavirus is to regularly wash your hands. We know that for some children and adults this can be difficult to achieve! Working with families we have put together some ideas to make this a fun activity, and we hope it is useful.



Washing your Hands



Widgit Find hundreds more symbol resources online at www.widgit.com

Remember:

- some days it will be easier than others, it will take time to introduce a new activity successfully
- try and introduce handwashing activities when your relative is relatively calm and happy
- “chaining” is important. You can break tasks into small steps, as part of a chain

Objects of reference

For people who use Objects of Reference for communication you might want to use an appropriate object as a prompt such as a piece of towel or a plug to represent hand washing and help them understand the activity.

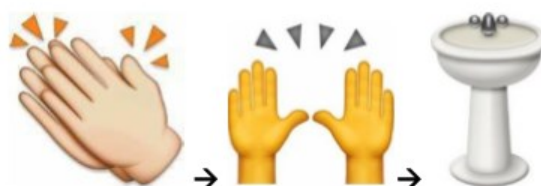


- although the aim is to wash hands regularly before meals, this may take time; don't try and introduce new handwashing activities when your relative is tired, hungry or anxious
- try to pick the activities that work best for your relative and repeat regularly so they learn what to expect
- as the weather gets nicer, paddling pools and buckets of water outside can provide extra opportunities for handwashing games
- use hand creams proactively. If skin is dry and sore, it will be very difficult to encourage someone to wash their hands. If possible, add using hand creams regularly to your routine after drying hands

Create a signal as a prompt for handwashing.

For example:

Clap hands, shake hands and then we go to the sink.



Handwashing games

Bubbles

1. Get a washing up bowl or a bucket
2. Explain to your relative using their preferred communication method that you are going to play with water and bubbles
3. Support them to half fill a bucket or washing up bowl with warm (not too hot!) water and place it on the table / in the bath/ in a suitable place which won't be damaged by splashing
4. Explain that you are going to make bubbles. Support your relative to add some washing up liquid or a small amount of bubble bath to the water. Offer them the choice (e.g. type of soap, colour or perfume). Try using products like Gelli Baff for variety
5. Show and explain that putting your hands in the water and moving them about makes bubbles

6. Encourage your relative to keep their hands in the water and make more bubbles. Join in, using the opportunity to apply extra soap and wash their hands as you make bubbles together



You find, I find

Set up the bubbly water as above. Explore other options in the bubbly water: e.g. Drop objects into the water (e.g. plastic fish or lego bricks). Ask the person to find the items. You could take it in turns (e.g. You find the fish? I find the fish)

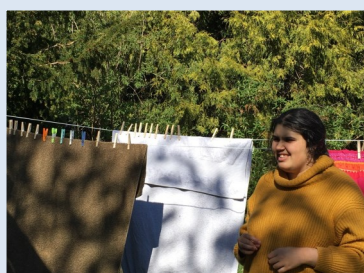


Top Tips from the Email Network

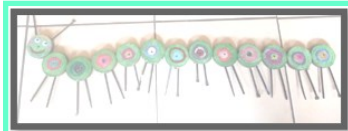
Families from our email network have shared some of their top tips and positive experiences during this difficult time.



Household tasks have become fun activities, such as hanging out the laundry, and mopping the floor to music. The image below is of Nadia making washing into works of art by putting a large number of pegs in certain sequences of colour when pegging up clothes. There's something surreal about a towel with fifty pegs on it.



Here are some photos of Zach during lockdown, he has coped really well despite all his favourite activities being closed. We were very lucky with the weather which made life easier! He flew a kite for the first time independently on a deserted beach!



Caterpillar made from small log sawn in to slices and painted, legs cable ties.



Laura's Tree of Hope

We have created our tree together, it has made us both happy, we have laughed, been excited, we have worked hard but well together. Yes I had to spend time with Laura and engage her at the level she understands but if she didn't have that engagement or stimulation or interaction with me, the outcome would be boredom for her and this leads to behavioural issues.

Please try and make a story with someone who would love it, Laura and I had a great time, created a great memory and we hope to do something else soon.

Thank-you all for listening to our story during Lockdown please stay safe everyone.

Kate & Laura x

Laura loved helping me look for materials around the house, she became so engaged.



She was able to choose from selected materials what she wanted, and that is so important as sometimes others tend to make choices for our children/adults without asking them!

The old pinecones were lying in the garden and I painted them with nail varnish



We used anything we could find in house or garden as we are in lockdown, plus it's free!

Thank you

Since our last newsletter we have had some incredibly generous donations from multiple fundraisers. We would like to thank everyone involved - we really appreciate the support.

Sixth form student John Spence, brother of CBF's Policy Officer, Mary, raised funds for the CBF with the Reading School Charitable Fund. They raised an impressive £1400 in November 2019.



After Local Champion Balwinder Sandhu's presentation to the Punjabi Society of the British Isles, the group subsequently raised money for the CBF. In November 2019, Balwinder was presented with a cheque for £2,001. Thank you to everyone involved.



Niamh Marron, student at Miskin College, raised £46.60 for the CBF by organising a collection during a performance. Thank-you to Niamh and to all those who donated

Support

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 is still operating and we hope that talking to people in similar situations might provide you with some additional comfort, advice and support.

The CBF are still working hard supporting families during this challenging period. 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 keep families informed.

A big thank-you to St Augustine's Sunshine Club, a local church group based in Ipswich, who sent the CBF a donation of £45 in the New Year.

Family Carer and local champion, Jackie Clarke was presented with a £1,110 cheque for the CBF in March. Thank-you to the 'Sloes' for their brilliant fundraising efforts.



Despite the London Marathon being foiled by Coronavirus, Carina and Ben are still planning to run the marathon to raise funds for CBF when it is rescheduled. They are following government guidelines by using their allocated exercise a day to continue to train. Training alone is hard work; if you can, please show your support for Carina and Ben by donating to the CBF via their fundraising pages

<http://bit.ly/BenCBF>
<http://bit.ly/CarinaCBF>

We understand that this is a difficult time for everyone, particularly for individuals with severe learning disabilities whose behaviour challenges and their families. We would like to take this opportunity to thank our volunteers and local champions who are continuing to help us support this group throughout this challenging period.

If you would like to help us in continuing to support families during this time please consider donating and 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 FOR YOUR SUPPORT

Can you help us?

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

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