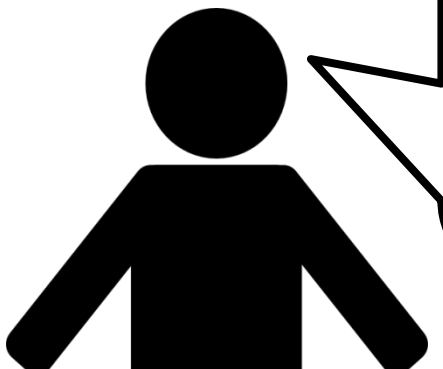


**Information Pack for Family and Friend
Carers During the COVID-19 Pandemic**
**Produced by Sussex Partnership Adult
Learning Disability Services**



We have put this pack together to support you during COVID-19 and to signpost you to information and resources which are already out there. We hope that they are useful to you.

(Sussex Partnership foundation Trust does not accept responsibility for any of the information in these documents as we are not the authors but we do think they are evidence based and useful.)



Challenges you might be facing

You may be facing a number of challenges at the moment due to the current crisis with the Coronavirus which is having significant consequences for both you and the person or people with a learning disability that you are caring for.

The person you care for may be struggling with not understanding what is going on. They may not be able to do their normal activities

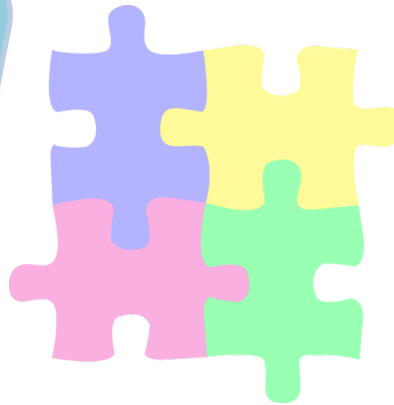
You may be struggling with understandable feelings of stress and worry

You may be needing a break and be missing support that you might usually have

You may be working as well as supporting members of your family or community

The person you support might be struggling with frustration and anxiety - they may be showing this through their words and behaviour.

The person you care for may be in the shielded group and you know the current lock down will be in place for you longer than for others



There are a number of small but significant steps that each of us can take to support our well-being during this time. The aim of this pack is to help you to be proactive in supporting yourselves and the person you care for in order to maintain their physical and mental health and to prevent additional needs from developing.

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Well-Being Checklist

	Page where resources can be found
Are you looking after your own well-being so you can care for others?	4, 5 and 6
Does the person or people you care for understand why things have changed? Has this been communicated in a way that is accessible to the person's level of communication?	7 and 8
Does every person have a predictable and meaningful routine throughout the day?	Page 8
Is every person's routine communicated to them in a way that is accessible to their level of communication?	Page 7 and 8
Does each person's day have a balance between times that they are alone and times they are with other people?	Page 9
Is there a plan for how each person will keep in touch with their family and friends?	Page 9
Is the plan for how contact with friends and family will be kept going clearly communicated to the person in a way that is accessible to their level of communication?	Page 9
Is there a clear routine night time routine that clearly marks the end of the day?	Page 8 and 12
Do you need to think about how to manage more difficult behaviour during social isolation?	Page 18

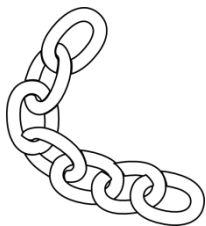
Supporting Your Wellbeing

It is important to think about how you support your own well-being. Feeling less resilient than usual is a normal reaction to the current circumstances. If you are struggling to cope then you are not alone. The presence of feelings of stress, anxiety, low mood or loneliness does not necessarily indicate psychological problems. There are many steps we can take to help ourselves feel more resilient. It is important to acknowledge that some of the strategies that individuals might usually use to reduce stress might no longer be available to them.

*Taking care of you
goes hand in hand with
taking care of others*



Try to think about how you need to adapt or rethink ways of coping and keeping well. It might be helpful to think about how you will:



Maintain connections and see social support from friends, family and your community



Take regular physical exercise



Get enough sleep



Create space and time to do activities that you enjoy

It may be that you are finding things more stressful or harder to cope with in the moment, at these times it can help to take a moment and rest, reflect and recharge.

REST

- Find a safe place where you can settle down for the moment and
- Close your eyes for a couple of seconds
- Take a few deep breaths
- Think of something that makes you feel happy

REFLECT

- Am I stressed out?
- What's stressing me out?
- Is it something that I can control? If it is , what can I do about it ? .. If it isn't, try to let it go.

REGROUP

- Get yourself ready before going back to the situation
- Take a few deep breaths
- If helpful, find someone to chat to

These organisations are offering support for people's mental health and wellbeing

- Sussex Mental Health Line on 0300 5000 101 available 24/7
- Free wellbeing support helpline: 0300 131 7000, available 7am - 11pm
- 24/7 text alternative to the above helpline - text FRONTLINE to 85258.

Try some of these free apps that can support emotional well-being:

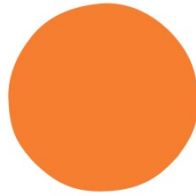


Happify
For Stress and
Worries



pacifica

Pacifica
Anxiety, Stress, &
Depression relief based on
CBT & Mindfulness



HEADSPACE®

Headspace
Meditation



INSIGHT
Peace in our Timer

Insight Timer
Meditation



Mindshift
anxiety
management

Supporting the Well-Being of the Person or people you care for

Talking to the person you care for about why things are different in their lives

How much does the person understand at the moment? Think about what and how much might be useful to share. Many people will be particularly sensitive to change. Noticing that things are different but not understanding why can be very confusing and distressing and we are all less likely to follow new rules if we don't understand why they are there.

It will be important to adapt the information to the person's level of understanding. Give information in little bits rather than all at once. Try and be consistent in the language you use (e.g. do you talk about Covid-19, Corona virus, the virus, germs?). Many people will need regular reminders and the information repeated. Back up communication using easy read or visual resources.

Social Stories

Social stories work best when they are adapted for a particular person and situation. Here are some ideas:

Places are closed

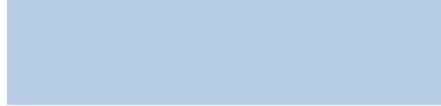


Places are closed
social story.pdf

Washing Hands



Washing hands social
story.pdf



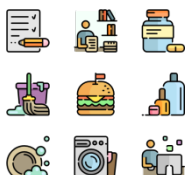
- **Social Stories to support residents if a friend/family member becomes unwell:**

When somebody I love is
sick



When+someone+die
s+from+coronavirus+

Keeping Routines and Meaningful Activity






Keep routines and keep busy: Try and keep the focus on what people CAN do rather than what they CAN'T. Remove activities that aren't possible from choice boards, timetables etc to reduce frustration.

Resources to support keeping busy:

- There is really good explanation about routines in the pack from:

<http://www.cardiffandvaleuhb.wales.nhs.uk/sitesplus/documents/1143/Supporting%20Children%20with%20LD%20&%20ASD%20with%20COVID%20Isolation.pdf>

- We are also attaching 3 documents that we developed - one relates to fun ways to engage people in exercise, one looks at some indoor art activities and sensory activities and the last is a collation of some general activities to try.

Exercise Resource	Sensory Art Ideas	Other Activities
 Selden-cise Exercise Resource Pack.pdf	 Sensory Art Ideas Pack_Easy Read Guid	 Senate doc activities.pdf

Maintaining Contact with friends, family and Professionals



Relationships are really important for all humans - without them we would not survive! Support from people we love and who love us is particularly important during times of stress. Different people will have different preferences for how to stay in connected - lots of us need more than one way. Encourage sending cards, photos or 'thinking of you' parcels. Body language and facial expressions are important and can help us to feel more connected to each other.

There are lots of ways of doing video calls examples include:

Skype



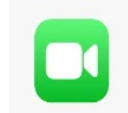
Zoom



WhatsApp



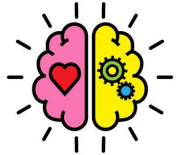
FaceTime



It is important to follow latest government guidance, which allows people with learning disabilities and autism to spend more time outside. We know how important this is for many people. This is a really good link to the most up to date information about going out and social contact.





<https://www.keepsafe.org.uk/posters>

Managing difficult feelings



Over the coming weeks it is likely that we will all have times when we experience difficult feelings. Difficult feelings related to the Coronavirus can be managed in the same way as difficult feelings about anything else.

Some resources that may help:

	There are some useful tips for talking about feelings here:	 Skills for Care Top-tips-feelings.pdf
	Some people might find it useful to complete a wellbeing journal adapted for current circumstances:	 Skills for Care Wellbeing-journal.pdf

Physical health

We know that people are already skilled in looking after physical health of the people they care for. At this time we need to be extra vigilant not only for symptoms of covid-19 but also for signs of physical health problems such as urinary or chest infections, pain, dental problems, and constipation which are frequently found to be the underlying cause of increased distress and behaviours that challenge in those less able to tell us about changes in their physical health using words. Careful monitoring enables physical health problems to be spotted and treated early.

The anticipatory care calendar looks ervy medical but it is quite easy to use and might be very useful in helping you decide if you need medical help.



ANTICIPATORY
CARE CALENDAR MO

We have also included a document on delirium as a reminder of how impactful it can be and what some of the underlying causes might be.



MindEd Easy Read
Delirium.pdf

Eating and Drinking Needs

For people with additional needs around eating and drinking it is important to consider the following:



- Mental health can affect eating and drinking behaviours, such as increased anxiety leading to faster eating pace and an increased risk of choking. Think about how to make sure the person is as calm as possible when eating and drinking - listening to music, watching a favourite TV programme, with people they like / with no people around , with distractions / without distractions

<http://helpstopchoking.hscni.net/pages/advice>

- Continue to seek GP and SALT advice if new concerns about the safety of eating and drinking arise
- Good oral hygiene remains important, especially as routine dental appointments are not accessible. Poor oral hygiene can lead to a range of poor health outcomes, including by increasing the pathogen load of saliva and increase risk of chest infections if saliva is aspirated.



Oral_health_a_quick
_guide_for_care_hon

Postural Support



If anyone you are supporting has posture or movement difficulty , the following information may be of help.



Your Posture
Matters.pdf

Sleep



Many of us are experiencing increased stress and unpredictable disruptive changes to our daily routines and our sleep can be affected. You may find the people you support experience difficulty getting off to sleep or waking during the night.

It is important during these times that we prioritise practicing good sleep hygiene and thankfully there are lots of small things you can do to ensure the best chance of good sleep.



- Support sleep with a routine
- Support people to go to bed and wake up at the same time each day.
- Try to help people avoid taking naps or sleeping during the day time where possible.



- Doing something that helps the person relax, such as reading a book or listening to some calming music can signal the start of a wind down process to prepare them for sleep.
- Foods and drinks that contain caffeine (chocolate or tea for example) act as a stimulant. Although alcohol can provide an initial feeling of relaxation, alcohol negatively impacts the quality of our sleep by preventing us from entering a state of deep sleep.

Create a Healthy Sleep Environment



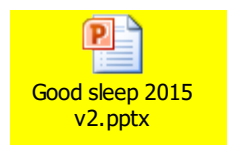
- Try to support people not to look at their phone or other screens about an hour before they plan on going off to bed.
- Make sure the room is not too hot or cold and that the room is dark.

Managing Worries about Sleep

- Currently there are constant news reports and updates on social media related to COVID-19. There is a natural anxiety around the impact of the virus and at the moment there is a lot to think about. If you think someone is struggling with racing thoughts, it can be helpful to write worries on paper and make a plan to manage the worry. Once you have this completed, put the paper away in a safe place to look at the next day.
- Worrying about sleep itself can be a vicious cycle. If you are looking after a person who is having trouble getting off to sleep, don't let them stay in bed worrying. Suggest getting up and go to another part of the house that is dimly lit and do something relaxing such as listening to some gentle music. When they begin to feel tired, try returning to bed again.



How Can I Find an Easy-Read Version of This Information?



Behaviour Support

Managing behaviour during the COVID - 19 crisis.

The people we care for, like us, will understandably be scared, confused, anxious about the future, cross that their lives have been significantly impacted and are far less likely to understand why. As with everyone else they may not be seeing the people they care about the most about and to make things doubly hard the regular staff that usually support them through changes and at times of flux may not be around for them. For those who display behaviour which challenges, we may see increased incidence of this happening. Those we care for who don't usually show behaviour which challenges may well begin to do so now. Below are some pointers which may help reduce the impact of the significant limitations being placed on us and the people we support.

Being proactive may seem nearly impossible at times, however it will be **by far the best way** to prevent, reduce duration, intensity and frequency of incidents of challenging behaviour.

Proactive

- Maintain routines and structure as far as possible.
- Encourage people to maintain regular sleep patterns.
- Getting up wash and dressed, as would usually happen on any normal given day.
- Alter daily/weekly timetables to reflect current government guidance of staying indoors. Try to make this as collaborative process as possible. The people we care for often have very little control over their lives and they have just lost even more. It's **really important** to find times they can have some control over what is happening. Ensure there is an accessible visual timetable to show what is happening through the day. The time things are happening are less important than the order that they happen in. Even people who can remember what is happening when told, having it visually is much more concrete for people and can be a lot more containing especially if a person repetitively questions what is happening and when. Complete the timetable each morning with the person.
- Setting up activity boxes in advance will help you not have to think too much when supporting someone through their day.

- Try to include activities though the day which include opportunities to achieve/be productive, i.e. completing daily living tasks, activities that are relaxing, those that bring joy and some that are physically stimulating. If people have a sensory diet/have had suggestions from an OT in the past it would be good to ensure these are being used.
- If tasks that usually happen can't such as going shopping, can they be achieved in a different way? Creating shopping lists on the computer, drawing ingredients they might want to buy. Helping to investigate where deliveries could come from.
- If people are particularly vulnerable and are unable to go outside at all, we may need to be creative with 'bringing the outside in' Open windows , fans, use of private outside space, sounds of nature music, apps that help you visualise a walk/activitiy.
- Some form of exercise each day is important for maintaining physical and mental health. There are numerous free websites and apps that can help with this if people are unable to go outside for their daily trip.
- Maintaining contact with important people adding into daily/weekly schedules as appropriate will be really important/being supported to use digital technology to accomplish this.
- Building in worry time to a weekly/daily/ schedule may be helpful for some. It would be more helpful if people could choose (if practicable) when and with who to have this with.
- If possible limiting the amount of news/COVID 19 information people are consuming it can be really frightening and there is a lot of inaccurate information out there.
- Reframe the situation and see if you can find the positives in the enforced lockdown, like we all are working through the jobs that have been at the back of the list. Creating photo albums, art projects, sorting out possessions, could review or create new goals/dreams/ activities that could be worked towards after the crisis has passed that could be incorporated into person centred plans. Think about how the indoor environment could be enriched.
- Ensure access to social stories about what is happening that can be easily revisited during tricky times.



Also remember that changes in behaviour and an increase in difficult behaviour can be due to physical health problems or because a person is in pain. You might want to talk to your GP about ruling out any health problems or use the information in the physical health section to think about this.

Planning for challenging behaviour

Challenging behaviour is functional; the behaviour serves a purpose for someone. That purpose could be:

1. To **get** what they want
2. To **avoid** something they don't want or find unpleasant
 - To avoid social situations they do not like
 - To avoid something they are being asked to do
3. To **communicate**, express themselves or gain **interaction** from others
4. To provide **stimulation** or to feel sensations that they enjoy

We all behave in ways that get our needs met usually in the easiest quickest way. Our behaviours are learnt and have been reinforced, i.e. they work, which is why we continue to do them. Ultimately in order to change challenging behaviour we need to teach a person a different way to get their need met.

Challenging behaviour is much more manageable when we can predict it and plan for it. You are the expert in the person you care for. A really helpful exercise will be to come up with a list of the things that the person you support finds 'triggering'. What are the situations they find difficult and would result in a behaviour you find challenging? These can include times of day, places, people, and actions.

From that try to think about why they are react that way in that situation; what is the function of that behaviour? What do they get? Avoid? Communicate or who do they gain interaction from? What is it they find stimulating about it?

Lastly when you have had a think about the situations/triggers that can lead to behaviour you find challenging and why the person behaves that way/ the function of the behaviour you can plan how to respond to it. Our response should be related to the function. In order for the behaviour to stop we need to meet the need. It is always better to plan for how you

are going to respond to difficult behaviour. Planning your response will help you stay calmer and not panic. Our emotions are contagious if we are seen to be calm and in control the person we care for is much more likely to be calm and in control. If we are angry/frightened and or panicking other people are also likely to feel those things and can their behaviour will reflect that. It is also really important that everyone in the household is on the same page and respond in the same way. If people don't respond in the same way it can be really confusing for the person and can sometimes make the behaviour worse. The exercise above is better written down, but if that feels too much, can just be talked through with the people around you. This process will be really helpful in reducing challenging behaviour. If you are able to have this conversation with the person who displays the challenging behaviour they may be able to tell what they want or need from you when things are hard.

What to do when things become Challenging

Everyone is struggling with being cooped up. If someone is struggling



1. **IDENTIFY** what the problem is "I know you want go out/are scared/bored"
2. **REFLECT** "I can see this is difficult"
3. **EMPATHISE** – "I would find this hard too"
4. **REASSURE** – "it won't last long, you're doing brilliantly"
5. **REDIRECT** – "let's do this fun thing instead"
6. **PRAISE** – "you calmed brilliantly" (even if this is not the case it is useful to thank the person for calming)

(The above also applies to you! You are all doing a great job!)

- Asking 'what do you want' and offering a means of communicating this can often be a forgotten first step. **Keep communication simple and clear but friendly at all times** When we are frightened/angry/panicking we don't process information very well. This applies to the person we support and ourselves. Visual information is processed more easily than verbal information so if it is possible to use a sign or a symbol great,

if not try to keep the amount you say to a minimum e.g. 'hands down, sit down' rather than 'Stop trying to hit me. That is not kind. You are going to hurt me if you carry on'

- **Redirect the person to something fun or interesting (favourite subject, change of scene, “look at that!” etc)**
- **Remove seductive objects BEFORE they become an issue**
- **Use the environment. E.g. Get behind the bed, give more space, back off** Consider where you position yourself e.g. across doorways, in front of the person blocking a means of escape. Try to put furniture in between you or stand with a clear way out for you or the person. If someone is being physically aggressive. Don't stay in a room unless it is more risky for you to leave than to stay. Objects are much easier to fix than people.
- **Try not to ignore the person even if you are trying not to comment on the behaviour itself**
- **Give the person what they want (if safe), to avoid a crisis. You'll only reinforce the behaviour if this is the one and only time the person gets what they are after – it won't be!!!**

If you are getting concerned about someone's behaviour or the situation is starting to feel like it may get unsafe, please contact us on the numbers above or contact your GP or emergency services if needed.

There are also a lot of carer organisations who are here to support you



carers organisations
doc.docx

