

## Trauma-Informed Care

# The Psychological Needs of People with Learning Disabilities Recovering from a Hospital Admission with Coronavirus

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## Introduction

Going to hospital when you are unwell at any time can be frightening. It can take time to recover emotionally. When people with learning disabilities go to hospital because they have coronavirus, there are extra difficulties that might make their experience seem even more frightening. This leaflet is to help families and carers to understand:

1) What some of the difficulties people with learning disabilities might face after a coronavirus related hospital admission

**AND**

2) What they can do to support the person as well as possible.



## Why is going to hospital with coronavirus more difficult for people with learning disabilities?

1) Visits from loved ones usually help to protect against the stress caused by a hospital admission. Due to coronavirus, family members and carers may not be allowed to go with or to visit them. This may increase feelings of loneliness and isolation, and provide less support than is normally needed.

2) Hospital staff will have worn a lot of personal protective equipment (PPE) making it harder for people to feel able to relate to them. For people with learning disabilities and autism where reading facial expressions and communicating can be difficult anyway, this can make interactions with hospital staff even more confusing and frightening too.

3) It can be more difficult to understand what is happening in a new, unusual and stressful situation (such as a hospital admission) for anyone. For someone with a learning disability they might not have all of the reasonable adjustments needed for the best chance of understanding and processing what is happening to them.

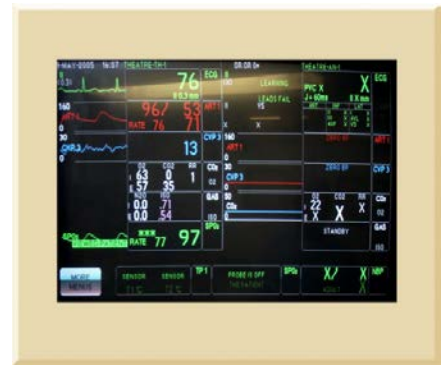


4) For those critically ill and in intensive care, they may see others sadly die. Trying to understand and process this, along with the 'what if' worries, may stay in the persons mind for a long time, whilst being difficult to communicate.

5) Hospitals are noisy places! There are lots of alarms, monitors and other noises that may seem twice as loud. Hospital lighting can also feel strange. If people with learning disabilities have different sensory preferences such as disliking touch, or being sensitive to noise, their stress bucket might be filled up with environmental factors from the hospital environment before even thinking about the impact of coronavirus on the person itself.

6) Having access to windows, natural light and nature are very important for wellbeing. There may be limited/no windows to access these important elements, keeping people 'stuck' in an unfamiliar environment with no link to the outside world.

7) The person's routine will change to fit with the routine of the hospital. This may be very difficult for someone who needs a set routine in order to help them manage the stresses of day to day life. Alternatively, they may get quite used to it, and may not wish to think of moving on! The person may struggle with understanding new rules, and the need to rest and recover.



It is important to say that most people recover well from a stay in hospital, even if they have been in intensive care. Some even experience more gratitude and personal growth.

However, about one third of people in the general population experience anxiety, low mood and other emotional difficulties such as flashbacks, nightmares and insomnia.

Although there isn't any specific research in to how people with learning disabilities recover from coronavirus yet, it is likely that similarly, some will recover well whilst others may experience the same or even additional difficulties associated with their learning disability.

These difficulties might be really distressing for both the person and yourself as a family member or carer but it is important to remember that they are a very normal and understandable part of processing what has happened and recovering.



## What might you notice as the person you care for returns from hospital?

The majority of people will experience fatigue on returning from hospital. They may find this frustrating, and it may take longer to do things. Conserving energy strategies may be needed.

- Some people may experience physical deconditioning such as finding it harder to walk, manage daily activities themselves, or eat and drink in the same way.
- Transitioning back to previously valued roles and routines may take longer and need to be done gradually.
- Some people may experience memory difficulties, attention difficulties, problem solving difficulties, or problems with making decisions and so on. People with learning disabilities already have cognitive problems but you might notice a deterioration from what you or they consider their baseline cognitive level to be.
- Some people may experience flashbacks on return from intensive care as their minds try to process the frightening experience.
- There is a high prevalence of insomnia and it can take a long time to get sleep re-established.



- Lots of people feel frightened of catching another infection and may become hyper-aware of their own bodily symptoms.
- Some people have been sedated during their hospital stay, especially if they were in intensive care. This can lead to additional confusion; some may have experienced delusions because it is harder to know what is real and not real when in a heavily sedated state.
- Some delusions have been reported to be about aliens which might be because hospital staff look so out of the ordinary with all of their personal protective equipment on.
- A general sense of heightened anxiety is a common experience and the physical symptoms of this (such as increased heart rate, feeling hot, difficulty breathing) may be believed to be coronavirus.
- People can often feel depressed on return from hospital as they try to process all that has happened to them and may seem unmotivated to engage with people or activities in the same way that they once would.
- Some people with learning disabilities may want to stay particularly close to their loved ones due to fears about being separated again.





## What can you do to help someone feel better?

### Normalize the person's feelings

Help people feel safe, calm, connected and hopeful. Reassure them that the anxiety, panic or low mood they might be experiencing is understandable, normal and should pass over time with the right support.



### Social contact

Help the person re-establish contact with loved ones as soon as possible. Telephone calls are helpful but video calls are better (although not too long as they can also be tiring) so the person can see their loved ones. Being able to see the faces, body language and hear the tone of voice of those we love is known to help us to soothe difficult feelings and enable us to feel calmer and safer.



### Nightmares and flashbacks

If the person you care for is experiencing nightmares and flashbacks, reassure them that they are home now and reassure them that this is their mind's way of trying to process what has happened. You could try the following grounding techniques to bring the person back to the present moment if they are hard to bring out of the flashback or nightmare.

- 1) Ask the person to tell you five things they can see in the room around them (or five colours).
- 2) Ask them to tell you which room they are in, in which house, which village/town and reassure them that they are not in hospital anymore.



### Sleeping routine

A good regular night time routine can be helpful for getting a better night sleep. See appendix one for our ten basic sleep routine principles!



## Making sense of what has happened

Help the person make sense of their journey (social stories, talking, pictures) and reassuring them that they made it through and have recovered is helpful. Encourage this but don't force it, be guided by the person and go at the person's own pace.

Look at what communication strategies the person used before going into hospital. Consider increasing the amount of communication support needed to compensate for fatigue and lack of concentration.



## Distraction

Use distraction, iPad's, music, radio, relaxation, signpost to the relaxation videos etc.



## Fatigue

Take a slow and graded approach to re-introducing activity. Try not to have some days with no activities and others full to the brim with activities, otherwise the person is likely to become over tired.

Identify small and realistic goals.

Try to avoid comparison to other people or to how the person was before.

- There are tips here on managing post viral fatigue and energy conservation strategies here:
- <https://www.rcot.co.uk/how-manage-post-viral-fatigue-after-covid-19>
- 'How to conserve your energy' guide: [www.rcot.co.uk/conserving-energy](http://www.rcot.co.uk/conserving-energy)



## Managing personal protective equipment and social connection

If you are a carer in a home using personal protective equipment, make sure you over emphasise other means of communication in order to offer comfort and compassion. For example, ensuring your body language is open and positive, perhaps holding hands and thinking about your tone of voice to compensate for other barriers in communication due to the effects of PPE.

If you need to wear PPE, take a photo of yourself without it to keep on you (or on a wall nearby) that you can point towards to help the person connect with who you really are.

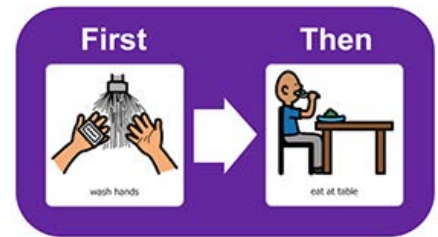


## Compensating for cognitive problems

Notice any changes in the person from what their normal baseline level of functioning used to be. Are there any changes in memory, concentration, how quickly the person can do things or how able they are to make decisions or solve problems? Jot them down so you can notice whether they are returning to baseline as they recover, or whether further support may be needed.

Use more visual aids to help the person orientate to where they are and what is happening that day (for example calendars, visual timetables, now and next boards) if this feels helpful.

If needed consider using social stories to help explain new tasks or demands that are expected of the person that day.



## Other ideas...

Getting the person back into their normal routine is very important and a predictor of a good recovery. This may take time and the person may have lost some confidence.

However, balance between encouraging them to regain the independence they may have had, but also don't be afraid to offer them more nurture and support than you might normally do whilst they need it.

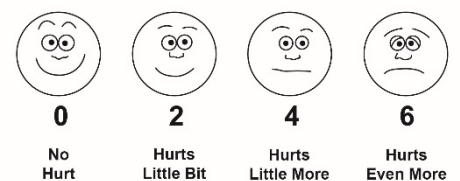
How are you responding to any remaining symptoms the person has? Understandably family and carers can feel very worried about symptoms but staying calm and seeking an objective outside opinion if you are worried might be more helpful than sharing the worries with the person concerned initially.

Use quick and easily likert scales (visual one to ten scales) for the person to be able to communicate their mood or level of pain to you.

Given all of the above, reduce expectations and demands on the person and encourage them not to be too critical of themselves too.

People may experience a sense of loss about the possible reduction in independence they have experienced as well as losses associated with others they have care about who have been affected by coronavirus.

Don't forget to look out for the persons strengths and the progress that they have made as well as seeing the difficulties!



## **If the above isn't enough?**

Recovering from the psychological impact of coronavirus will take time. It is normal for the person to struggle on their return from hospital. Reassuring them, giving them time and following the advice in this booklet will help them to feel more settled over time.

However, for some people they may need additional support from health care services. If after trying the advice in this leaflet the person you support is still showing a high amount of distress and/or struggling to return to activities, routines and roles then please contact your GP or local learning disability team for further advice and support.



## **What about you?**

In previous pandemics, around one third of family members interviewed showed signs of PTSD after a hospital admission of a loved one so think about you too! There is a correlation between relative's level of distress and patient recovery, so self-care is not only important for you, but also for your loved one too.

See appendix two for online wellbeing resources.





## **Appendix One**

### **Top 10 Tips for Good Sleep**

#### **1. Tech free bedtimes!**

- Bedroom is a place that should be associated with sleep.
- Other day to day activities should be done in other rooms.
- With technology, the “backlit blue light” displays suppress melatonin.
- This causes sleep disruption.
- It is recommended that you should stop using these devices at least 2 hours before you go to sleep.

#### **2. Prioritising the Management of Physical Symptoms!**

- Anyone who is struggling with physical health problems like a blocked nose or a headache will struggle to get a good night's sleep.
- It can be easy to forget minor symptoms, so it is important to consult with your pharmacist or GP about appropriate treatments for symptom management.

#### **3. Light, Sound, and Temperature.**

- Never underestimate the investment of eye masks, earplugs blackout blinds and anything that gives greater control over the environmental conditions

#### **4. Dealing with Worry**

- Forcing yourself to sleep and thinking about sleep too much will not help and is detrimental.
- Grounding and progressive relaxation techniques are very useful.

#### **5. Foods That Help and Hinder**

- Along with the obvious one of caffeine things high in sugar and a big meal mid evening can hinder sleep.
- However, eating rice, oats and dairy products can produce chemicals that increase the desire to sleep.

#### **6. Alcohol Alert!**

- Alcohol can make you feel tired before bed but more often than not, it impairs the quality of your sleep and you are more likely to wake up.

#### **7. Timing Your Exercise.**

- Exercising on a regular basis can help you sleep.
- It also helps reduce anxiety and relieve stress
- Exercising early during the day is better as exercise increases adrenaline

#### **8. No Napping!**

- Napping does more harm than good and makes it more difficult to sleep at night.
- If you feel tired during the day you should get up and engage in some physical activity or get some fresh air.

#### **9. If You're Not Tired, Get Up!**

- If you are struggling to sleep get up and do something, e.g. have a drink (no sugar or caffeine)

#### **10. Keep a Sleep Diary.**

- Keep a diary of the conditions when you went to bed. This way you can work out what conditions are best for you.
- This would also allow you to analyse patterns in your sleep.

## Appendix Two

### Wellbeing Resources

#### Websites and Apps:

- 1) *Mindful exercises for everyday life (Solent NHS Trust) FREE.*  
<https://www.youtube.com/playlist?list=PLFbeQlTqQPGTLAmNgKs0srX9Vau7mctFf> A series of mindfulness, ACT and compassion-based exercises found on You Tube.
- 2) *Mindfulness: Finding Peace in a Frantic World (Danny Penman) FREE.*  
<http://franticworld.com/resources/> Includes recordings of the body scan, 3-minute breathing space, chocolate meditation, mindfulness of the body and breath, befriending meditation etc.
- 3) *Compassionate Mind Foundation* <https://www.compassionatemind.co.uk/resources> *Compassionate Mind Foundation website (FREE)* Recordings of addressing self-criticism, building the compassionate mind, posture, faces and tones, soothing rhythm practices.
- 4) *The Happiness Trap App* is free for the next three months due to the corona virus outbreak. Download the App from Apple app store and then enter the code: TOGETHER on the subscription page to unlock all the app contents.

#### Free Audios:

- 1) <https://jackkornfield.com/compassion-in-the-time-of-coronavirus/>
- 2) <https://jackkornfield.com/steady-heart/>