Caring for someone with a learning disability who is self-isolating/social distancing due to risks associated with Coronovirus

Unexpected change and loss of social contact and routines at this time can be a distressing experience for anyone, however individuals with a learning disability are particularly vulnerable. Some people may adapt quicker than others. However the uncertainty and ongoing change surrounding community support will impact on many individuals who rely on structure and routine.

Key principles when supporting someone to adjust and adapt to change is to provide predictability and consistency to promote safety and trust.

Promoting wellbeing

These are some suggestions:

Communication

- There are a number of accessible information guides on the internet to support people with a learning disability to understand the current situation (see https://www.scld.org.uk/information-on-coronavirus/). For others, this will be too much information and they may respond better to a short, concrete verbal and/or visual explanation e.g. communicating “Day centre closed, home today”.
- Do not talk about Coronovirus unless you are talking directly to the person in a way they will understand. They may not understand all of what is being said which can lead to further distress. This also applies to television programmes e.g. news, social media.
- When there are multiple carers supporting one person, consistent responses in the form of ‘scripts’ for key issues causing the person a level of distress, can support an individual to feel more secure e.g. “Day Centre closed, home today” rather than variations each time. Write down the agreed scripted responses and ensure everyone communicating with the person is aware of them to ensure consistency.
- If staff are required to wear protective clothing this could be quite frightening. Take photographs of carers wearing masks if that is the case, and show the person saying “look, this is me” while pointing.

Structure

- Develop a timetable for the person’s day. Start with their morning routine. The remainder of the day might be structured by a mixture of activities of daily living (e.g. morning and bedtime routines), domestic activities (cooking, cleaning), leisure (arts and crafts, books/magazines). The same activities can be used for each day.
- Some people have particular sensory needs. If you know what their needs are, try to build some sensory activities into their day such as movement and exercise at home, walking around the garden area, kicking a ball, hand massage, playing with materials/soft toys, hand muff, sensory box etc.
- Introduce a hand-washing routine. Demonstrate and place visual reminders above sinks.
- If the person is not self-isolating (and health and levels of support allow), include a walk in their timetable. Consider how you will communicate the 2 metre rule to the person (e.g. pictorial reminder)
- The person may no longer be able to purchase preferred items at the shop. It may be helpful to organise for shopping to be delivered.

- If the person has a communication aid such as a visual timetable, use this to support them to understand what is happening in their day, or if they can read, write a list (e.g. 3-4 activities at a time). Others may only cope with 2 activities at a time (i.e. communicate ‘now and next’) and some will only be able to predict what is happening next by handing them an object from a particular routine e.g. colouring pens for colouring in, wooden spoon for baking.
- If the usual procedure is to attach photographs of carers to their timetable then continue as usual but also put photographs of carers with protective clothing beside their existing photograph (if required to wear protective clothing).

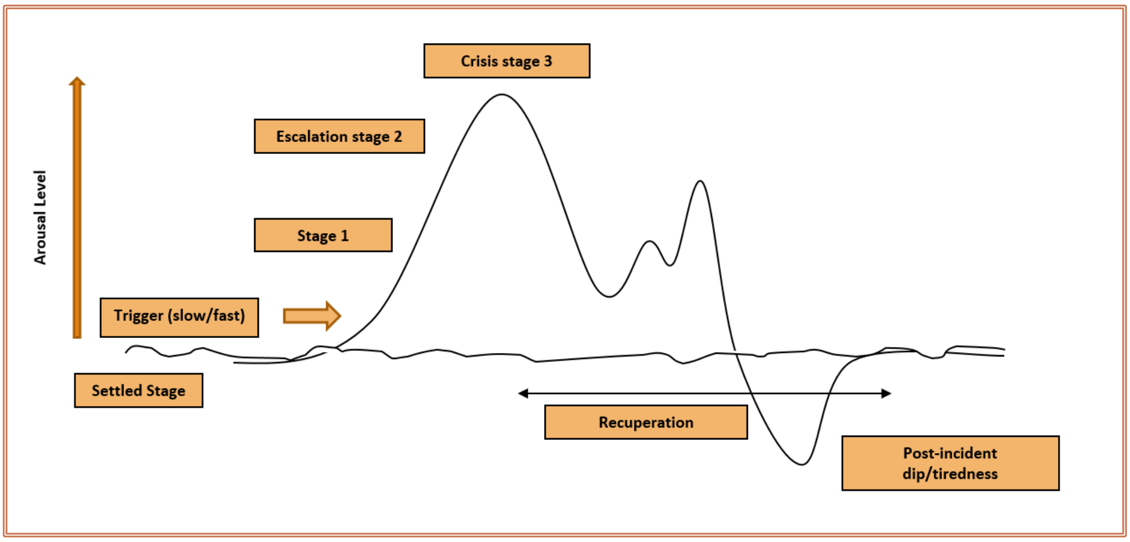
Relationships

- Support the person to maintain important relationships by using the phone/Facetime/Skype etc. It would be helpful for all family/friends to have an agreed explanation for why they are not visiting.

Responding to episodes of distress

Some people you support may need help to contain their distress. If they already have a reactive strategy or a behaviour support plan, please refer to this.

Distress comes in many forms, and is different for everyone. When someone is showing signs of distress, they may show more subtle signs to start with (e.g. withdrawal, repetitive speech, faster movements, hand flapping etc.) which escalate over a period of time to crisis stage (e.g. throwing objects, punching, kicking, banging head off surface etc.). This is a diagram of how distress and behaviours communicating distress can escalate over time. There are general principles which you can apply when supporting an individual to cope with their distress.



Stage 1

- Try to remain calm and model calmness in your own behaviour/communication. This can be difficult to do when you are experiencing a level of stress yourself. Slow down your movements and speech
- Maintain their current routine as much as possible
- Reduce verbal interaction to key words

Stage 2

- Limit verbal communication with the individual. Do not try to reason with them, as their understanding will be significantly impaired.
- Say the person's name to gain their attention before directing them to a calming activity (something they enjoy that is not going to be too stimulating or exciting)
- Some people need space; others like to be close to their carers. This is individual to the person you are supporting
- For people that can tolerate close contact, it can help to sit down with the person and listen to them. You do not need to provide responses. This may be an opportunity to use 'scripts' or go over a social story
- Some people may respond to consistent use of positive phrases such as "David is safe", "David is okay", "David will feel better soon".
- If the person has a history of picking up/throwing items/hitting out, make sure the environment is safe e.g. cooker off, ornaments/sharp objects tidied away, direct other service users or the person you are supporting to a different area of the house.
- If the person is prescribed 'as required' medication, it is helpful to administer before the levels of distress become unmanageable. If they have one, please refer to person's 'as required' medication protocol/administer as per medical professional's advice.

Stage 3 – is about establishing and maintaining safety

- The individual will have limited understanding of verbal information, only use key words
- Keep yourself safe, give space. Monitor person's safety
- Follow organisational procedures or contact appropriate services for help

Recovery/Recuperation/Post-incident

- It can take some time to fully recover from high levels of arousal due to the stress hormones in the person's body
- Keep this period as calming as possible
- The person may be tired and tearful and need to rest
- Do not debrief the person
- The person may seek a lot of reassurance, use simple phrases "its finished", "its okay".

Self-care for carers

Caring for someone with a learning disability who is experiencing episodes of distress can have an impact on your own mental and physical wellbeing, particularly so at this current time, as you may also have a range of other stressors in your life e.g. worries about the wellbeing of your own/other family members, finances etc

There is some information on the NHS inform website and other online resources on tips for self-care at this difficult time.