Surrey and Borders Partnership NHS Foundation Trust

## Coronavirus

## A trauma-informed care approach to supporting people with learning disabilities

## A guide for families and carers

By the clinicians of CTPLD East (Dr Elisabeth Goad, Clinical Psychologist, with advice from Lindsey Mosley, Occupational Therapist and the rest of the Occupational Therapy and Speech and Language Therapy Team)

#### What is 'normal' anxiety right now?

- With constant news stories about Coronavirus overwhelming our daily lives most of us will be living in a state of heightened anxiety.
- Daily conversations, radio, TV and social media make it difficult to 'take a break' and give ourselves moments of calm from the anxiety that this experience is inevitably causing.
- Many people are worrying about who will and how many will get ill and possibly die; the impact on families, finance, education, employment and housing is likely to take its toll.
- People are experiencing some difficult but very normal feelings such as anxiety, fear, anger, irritation or sadness.

#### Coronavirus as a traumatic experience

- Relationships are extremely important to human beings because without them we could not survive.
- □ When relationships are threatened in some way, we have an inbuilt and intense psychological and emotional response (think about all the things that upset you deeply, how many of them relate to something between you and another person?).
- If threats are intense or prolonged in some way, we can get stuck in 'fight, flight or freeze' responses.
- People are more likely to feel traumatized when they feel helpless or have a lack of control over a situation.

#### Coronavirus feels like a constant threat to relationships because...

- People are having to self-isolate from those who they care about or whom they depend upon on.
- D People fear the impact of illness and death for themselves and others.
- There is a reduction in ability to engage with activities outside of the home where social connectedness may have played a key role.
- □ Strained relationships where families are forced to self-isolate together with limited opportunity for personal space.

□ There is a disruption from normal social networks, schools and friendships for children, employment and social groups for adults.

#### Our threat systems are likely to be activated all of the time!

## Coronavirus and people with learning disabilities

In addition to the anxiety experienced by the general population, people with learning disabilities will also have additional issues and needs:

- 1) The fact that people they may depend on to meet their health, social and emotional needs may not be able to support them anymore.
- If social care providers start to struggle with staffing their services; people with learning disabilities may be cared for by people they do not know and find hard to trust.
- 3) It may be harder for people with learning disabilities to understand what is happening in the world and what Coronavirus means for them.
- 4) Their routines that are often so important to them may have been disrupted.
- 5) Substitute activities may not be practical or accessible.
- 6) Transition and change is often very difficult for people with learning disabilities.
- 7) Access to activities that are specifically regulating for people may be reduced.
- 8) As colleges, day services and opportunities for other meaningful engagement close, loneliness and its associated mental health problems become a real concern.
- 9) Strained relationships may occur as families rearrange their lives to provide more of their own support to people with learning disabilities whilst managing their own anxieties around health, housing, employment and finance.

## What might family and carers notice in themselves?

- Being preoccupied with the news, constantly 'checking' for updates.
- □ Finding it difficult to focus on day to day activity.
- Feeling 'uptight or tense'.
- □ Increased muscle tension, increased heart rate, chest tightness, increased breathing rate, fatigue, changes in sleeping patterns.
- □ Losing their own self-care routines to prioritise the care of others.
- Feeling less patient and more irritable than you typically would.
- Normal but increased feelings of anxiety, fear, worry, sadness, anger.

# What might we notice in people with learning disabilities?

- □ Preoccupation with the news, constantly checking for updates.
- □ Finding it difficult to focus on day to day activity.
- Feeling 'uptight or tense'.
- □ Increased muscle tension, increased heart rate, chest tightness, increased breathing rate, fatigue, changes in sleeping patterns.
- Increased health anxiety, worry about getting ill, increases in 'checking' behaviours.
- Experiencing (normal) feelings of anxiety, fear, worry, sadness, anger.
  AND
- Withdrawing and disconnecting from others, feeling frightened to go outside.
- □ An increase in behaviours that challenge, often anger and associated anger may be an external representation of underlying fear.
- An increase in psychosomatic symptoms (physical symptoms without a physical cause).
- Seeking more reassurance than normal to help manage the constant daily changes evident in their lives.

## What can we do to help?

#### What does the person understand?

- How much does the person understand what is happening at the moment? Think about what and how much might be useful to share with them. Use easy read or visual resources to back up communication if needed (see resources below).
- Offer time for the person you support to talk to you about their concerns regularly. Providing open but containing communication will help them feel less alone.
- □ Consider how much 'Coronavirus' talk there is around the person with learning disability? Is it helpful information giving or is it escalating anxiety?

#### Managing mental health

□ Limit time spent watching news stories, set a time of day when you will catch up with what is happening and try to support the person to engage with other activities during the rest of the day.

- Help the person make a 'worry box' where they can write down or draw their worries and put in the box to help them feel that their worries can be 'held' outside of their own minds. Encourage the person to share what's in their box with you once a day if they want to.
- Try to avoid conversations about Coronavirus just before bed to encourage sleep.
- Develop your own self compassion, you may experience difficult feelings that make you act in ways you wouldn't normally. Be forgiving.
- Relaxation and mindfulness-based activities can help calm busy minds AND calm the physiological reactions of trauma and anxiety. Practicing regularly, even when you feel calm will increase their efficacy. See resources below for free links to online exercises.
- Update and review support plans to reflect the changing and dynamic support needs people are likely to have.
- Support the plan to take individual control over whatever they can to reduce feelings of helplessness. Control over hand washing, opportunities to help others and so on can help to help people feel more in control

#### **Regulating activities**

- □ When we are **stuck in 'threat' mode** all of the time, we all have certain activities that help to **calm us down**.
- Focus on activities that use muscles and get the person moving. Day to day tasks that can be regulating include hoovering or carrying the laundry. Leisure activities might include stretching or yoga.
- □ Think about what activities usually calm the person and more specifically what it is about that activity that calms them.

#### Staying connected

- Body language and facial expressions are important and help us to feel more connected to each other than just hearing a loved one's voice on the phone. As such, find ways to use platforms such as Skype, Teams, Facetime or Zoom to maintain connects where face to face contact is not possible.
- □ If the person with a learning disability is self-isolating away from their family encourage sending cards in the post, sharing of photos or 'thinking of you' parcels to help combat loneliness and reassure the person that those who are not with them are thinking about them.

#### Structure, routine and meaningful engagement

- □ Create a home time daily structure and routine (see resources below).
- Are their opportunities within the home to learn new skills or do valued activities together?
- Ensure activities are a mixture of pleasurable, achieving and socially connecting.
- Developing meaningful roles for everyone at home can help raise selfesteem and maintain purpose at a time where purpose may feel as though it has been lost.

#### Staying fit and healthy

- Get fresh air when you can, walks and runs are still acceptable as long as you keep your distance from others.
- As best you can, support the person to keep eating healthily and keep moving. Walking and running is still acceptable as long as you keep your distance from others. There are lots of exercise classes free online.
- Develop a wellbeing plan with the person, how can you support them to maintain good physical, mental, spiritual and emotional health in creative ways?

#### Look after yourselves

- Put on your own oxygen mask before you start putting on everyone else's!
- You are important too. Try to maintain your own self-care routines as much as possible. If this is a marathon not a sprint you will need energy at the end.
- If you have not had a recent carers assessment, please request one from your local social care team if you would like too.
- Please also follow the guidance below, managing your own routines, social connectedness and mental health will be vital in helping you to stay well and continue being able to support the person you care about.

## Resources

## Advice for carers

<u>https://www.carersuk.org/help-and-advice/health/looking-after-your-</u> <u>health/coronavirus-covid-19</u>

## Easy read leaflets on Coronavirus

https://www.dropbox.com/home/1.%20Wellbeing%20%26%20mental%20health ?preview=Easy+Read+-+advice-on-the-coronavirus-v1.pdf

https://www.dropbox.com/home/1.%20Wellbeing%20%26%20mental%20health ?preview=Easy+Read+-+Information+about+Coronavirus+.pdf

https://www.dropbox.com/home/1.%20Wellbeing%20%26%20mental%20health ?preview=My+Name+is+Coronavirus.pdf

https://cdn.shopify.com/s/files/1/0606/1553/files/Coronavirus-Poster-2-Photosymbols-UK.pdf

https://cdn.shopify.com/s/files/1/0606/1553/files/Coronavirus-Poster-3-Photosymbols.pdf

https://cdn.shopify.com/s/files/1/0606/1553/files/Coronavirus-Poster-1-Photosymbols-UK.pdf

## Social story templates about Coronavirus

https://www.flipsnack.com/KeshetChicago/coronavirus-social-story/fullview.html

https://aaccommunity.net/2020/03/covid-19-board/

https://theautismeducator.ie/wp-content/uploads/2020/03/The-Corona-Virus-Free-Printable-.pdf

## Developing a routine during Coronavirus

https://www.rcot.co.uk/staying-well-when-social-distancing

https://sensoryproject.org/2020/03/16/sensory-stuck-at-home/

Google, 'boredom busters Coronavirus' to get some great ideas of things you can do together at home.

## General mental health support

<u>https://www.mentalhealth.org.uk/publications/looking-after-your-mental-</u> <u>health-during-coronavirus-outbreak</u>

#### Manging OCD during Coronavirus

https://www.ocduk.org/ocd-and-coronavirus-survival-tips/

## <u>Relaxation and mindfulness (for families, carers and people with</u> <u>learning disabilities)</u>

Compassionate Mind exercises:

#### https://www.compassionatemind.co.uk/resources/audio

**The Happiness Trap App** is free for the next three months due to the Coronavirus 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:

https://jackkornfield.com/compassion-in-the-time-of-coronavirus/

https://jackkornfield.com/steady-heart/

#### Mindful exercises for everyday life (Solent NHS Trust) FREE

https://www.youtube.com/playlist?list=PLFbeQlTqQPGTLAmNgKs0srX9Vau7mc tFf

A series of mindfulness, ACT and compassion-based exercises on you tube.

## Mindfulness: Finding Peace in a Frantic 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.

<u>The https://www.compassionatemind.co.uk/resourcesCompassionate Mind</u> Foundation website (FREE)

Recordings of addressing self-criticism, building the compassionate mind, posture, faces and tones, soothing rhythm practices.

#### Apps

Headspace - free trial and then subscription required after that Calm -free trial and options to pay for additional functions if you want to) Aware - free (you can pay for additional functions if you want to)