

## **Supporting people who have learning disabilities and/or autism**

### **Understanding Coronavirus – Easy-read Guidance**

A range of easy-read information is available from a range of sources (e.g. Mencap; Down's Syndrome Association; Books beyond words etc.)

The following resources can be reviewed with people to assist them to understand coronavirus and how to protect themselves:

- Information about Coronavirus (COVID 19) – Mencap, 2020
- All about COVID 19 – what to expect – Mencap, 2020
- All about COVID 19 – What does social distancing mean? – Mencap, 2020
- All about COVID 19 – What does self-isolating mean? – Mencap, 2020
- What should you do if you think you have Coronavirus? –Mencap, 2020
- Jack plans ahead for coronavirus: a guide for family and carers – Books Beyond Words
- Good days and bad days during Lockdown – Books Beyond Words

The following resources are also available if a person with disability or their family member of carer develops the COVID 19 illness

- What will happen if I do have COVID 19 – Mencap, 2020
- What will happen if I have to go to hospital because of the coronavirus?, Mencap 2020
- All about the coronavirus – what to expect if someone I know goes into hospital – Mencap, 2020
- When someone dies from Coronavirus: a guide for family and carers – Books Beyond Words

### **Guidance for Families and Carers during the COVID crisis**

People with learning disabilities and/or autism require a very concrete, literal and predictable world in order to feel safe and secure. This has become increasingly

difficult to achieve during the COVID 19 restrictions. The following guidelines may be helpful to support people at this time

### **Maintain structure and routines**

- Maintain structure and daily routines where possible. Keep familiar routines throughout the day to optimise predictability and certainty e.g. time to get up and go to bed; time for meals etc.
- If necessary, limit changes to the person's routine by replacing usual activities with equivalent/similar activities (e.g. maintain the usual structure of going to the day centre from 9am – 3pm by planning home based activities at these times).
- Help the person create new positive daily routines that provide choices, responsibilities (where possible), challenges and engaging activities. Include familiar and favourite activities. Use Choice Boards or Talking Mats™, if available
- Only offer choices that you can deliver at that time/remove activities from schedules that are not possible at this time
- Support the person to learn new skills and develop meaningful roles in the house –this will build confidence and self-esteem
- Try to avoid changes in key familiar people e.g. domiciliary workers; social worker etc.
- Use visual schedules/timetables/checklists (written or pictorial) to help the person understand what is planned for the day/week
- Use prompts for the person to transition between activities e.g. countdown clock; verbal reminders; etc.

### **Healthy Daily Routines**

- Information regarding COVID 19 – there is an enormous amount of new information every day which can be difficult to process and can be overwhelming. Limit information to essential news only (e.g. provide brief overview of essential facts; limit watching news to once per day from a reliable source; turn off notifications on phones; ensure the TV or radio are not playing continuously in the background; etc.). Watch television with the person, where possible, to provide a context to the news and answer questions
- Replace negative terms with positive ones e.g. 'this is how we will stay healthy' rather than 'how we will not get infected'
- Counterbalance negative news – each evening identify 3 positive/good things that happened that day

- Sensory difficulties – some people may be overly sensitive to sensory input e.g. noise/smell/touch etc. The requirement for frequent hand-washing can create difficulties for some people. The following strategies may help
  - Use unperfumed/unscented soap
  - Use a wet towel with soap soaked in to wipe hands
  - Use visual or music timer to prompt how long to wash
- Maintain a consistent sleep routine and healthy diet
- Provide opportunities for exercise and keeping fit – e.g. walks in the fresh air; free on-line exercise classes etc.
- Provide opportunities for spirituality and religious expression, where relevant

### **Social relationships**

- Social contact – help the person to continue their friendships and contact with family – the person may require specific guidance or assistance to text/call/skype their family and friends or to send cards by post
- Social interaction – some adults will enjoy the reduced social interaction which is a consequence of COVID 19. However, in order to avoid difficulties of isolation, agree forms and frequency of communication e.g. via text/video calling etc. at specific times of the day
- Provide opportunities for the person to help others in the house – helping others is good for our well-being
- Celebrate significant events e.g. birthdays; friend recovering from illness etc.

### **Coping with change in routines**

People will be required to cope with change when typical routines are not possible to maintain. The following strategies are recommended:

- Support the person to understand that change is a part of life for everyone at the moment
- Give advance warning about the change, where possible
- Find out what the person already knows about the planned change and encourage them to communicate how they feel and what they want. Acknowledge and normalise the situation e.g. “we are all feeling a bit worried about the day centre closing”
- Consider the use of social stories or photo storybooks to aid understanding (Social Stories™ provide guidance for responding to social situations – through the use of images or photos to present the situation)

## **Managing stress and anxiety**

Many people with learning disabilities and/or autism will be experiencing heightened anxiety and worry at this time

### Causes of stress and anxiety

There are multiple changes to our lifestyle that could cause stress and anxiety for people with learning disability and/or autism

- Changes to daily routines – including not being able to go to usual activities
- Changes to staff providing support (e.g. if regular care staff are temporarily replaced) or changes to residents in the unit
- Changes in access to preferred foods and shopping routines
- Reduced access to staff to complete non-essential activities (if reduced staffing levels available)
- Access to substitute activities may not be practical to maintain
- Some people may move from independent or supported living to return to live with family members during the COVID crisis. Equally some people may need to move out of their family home if their carer becomes unwell
- Family members or carers may be experiencing their own heightened stress leading to strained relationships

### Signs that person may be experiencing heightened anxiety

- Physical signs of anxiety e.g. increased muscle tension; change in rate of breathing; change in sleep pattern etc.
- Person may report feeling anxiety; worry; sadness; anger etc.
- Person may be preoccupied with news and constantly checking for updates
- Person may report increased health anxiety; worry about getting ill; increase in checking behaviours; increase in talking about deceased relatives; etc.
- Person may have difficulty focusing on day to day activities
- Person may withdraw and disconnect from others e.g. stay in own bedroom
- Person may repeatedly seek reassurance from others

### Supporting people who are experiencing stress and anxiety

- Provide quiet time and space for the person to talk about their fears and worries
- Encourage person to use their usual coping skills rather than focus upon developing new skills
- Encourage person to engage in active exercise or movement – this can reduce anxiety. On-line yoga and relaxation classes can be accessed

- Limit time watching news stories and talking about coronavirus
- Assist the person to take control over their day to day activities, where possible
- Encourage the person to develop self-calming strategies. These could include:
  - Taking deep breaths to reduce level of arousal
  - Counting to 10; repeat soothing self-statements; recite a few words/lines of favourite song, etc.
  - Engage in favourite activities e.g. listening to music; watching favourite television programme/DVD; engage in crafting/ jigsaws etc.; engage with sensory activity (e.g. rocking in a chair) etc.
  - Encourage person to state or write down their worries - put worries in a 'worry box' so that they can forget about them until another time

### **Managing behaviours that challenge**

During the COVID 19 crisis people's anxiety levels and behaviour may escalate and be a specific cause for concern. The following guidelines are recommended in supporting a person's behaviour

- Always first consider a possible underlying physical cause for any change in behaviour – obtain an assessment with a GP if you feel the person may be unwell. Ensure that the person has an up-to-date Hospital Passport if they are likely to need medical treatment at this time
- Review if environmental changes are having an impact on the person and identify ways to alter these changes
- Ensure that you have access to the person's Positive Behaviour Support Plan and Communication Plan, if available
- Remind the person of the behaviour rules – allow plenty of time for the information to be processed. Avoid asking lots of questions
- Assist the person to express themselves and say what is causing their behaviour, if known. Provide extra reassurance to the person, if relevant
- Praise and reward positive behaviours. Increase access to preferred activities – these are short-term changes to accommodate a crisis
- Reduce demands and expectations that person finds difficult to complete – e.g. person may need support to complete a task that could have previously completed independently
- Review known triggers for behaviour and put in place strategies to mitigate these
- Watch out for early warning signs that person's behaviour may escalate – and intervene as soon as possible

- If the person's behaviour becomes challenging
  - Stay as calm as possible – use low voice; relaxed body movements and gestures
  - Keep your language short and simple; use simple gestures to explain what is required; model tasks that you want the person to do e.g. sit down
  - Give the person space and time to settle
  - Increase your personal space/ distance from the person –withdraw from the situation, if it is safe to do so
  - Divert or distract the person with other activities – meet any reasonable requests, where possible
  - Consider prn medication or physical intervention only as a last resort – use PPE where relevant
  - Keep a record of what happened before, during and after the incident
  - Ask for help from the Community Learning Disability Team or other specialist services – they may provide advice over the phone or in person

### **Mental Capacity Act**

People with learning disability and/or autism may require to be deprived of their liberty if they do not have capacity to understand the requirements of government restrictions (e.g. social distancing; self isolation etc.). The Coronavirus **Act 2020** and mental capacity emergency regulations should be followed in such circumstances.

### **Caring for the carers – take care of yourself**

Caring for a person with learning disability or autism can be an incredibly rewarding experience. However, it can also create an added responsibility. It is essential that you take care of your own needs so that you can stay healthy and well to take care of the person with disability. Remember 'this is a marathon, not a sprint' – it is important that you 'put on your own oxygen mask before helping others'.

It is also useful to create an 'Emergency Plan' if the person is living at home - this should outline what will happen if the main carer is unable to look after the person with disability (this may include telephone numbers for other family members; social worker etc.).

