



the british
psychological society
promoting excellence in psychology



Division of
Clinical Psychology

Faculty for People with
Intellectual Disabilities

GUIDANCE

Covid-19: Meeting the psychological needs of people with learning/intellectual disabilities, and their families and staff

People with learning/intellectual disabilities in the UK are experiencing the Covid-19 pandemic in different ways. Their responses will vary across time as the situation continues to unfold. Their experience will depend on their personal history of power and threat, attachment and loss, their individual psychological resources, resilience and intellectual strengths, their physical health and sensory profile, the information available to them, their coping strategies, social relationships, their economic circumstances and their physical environment.

PROTECTIVE FACTORS

For some people with learning/intellectual disabilities, the Covid-19 lockdown restrictions, at least initially, are a protective factor. Some are not having to venture out into a stressful world that requires complex decision making, attention to personal, financial and road safety or responses to sensory challenges, teasing, bullying and abuse. They may not be faced with the usual risks associated with their behavioural choices such as smoking, alcohol, gambling, sexual activity or about drug taking or other illegal activity. They may not have to be spending as much money as usual. They may have access to information about Covid-19 in ways that they find sufficiently reassuring despite the ongoing threat. Covid-19 Hospital Passports have been created and shared in readiness with hospitals.

Many people with learning/intellectual disabilities either live with or are supported by family or staff with whom they have a positive attachment. At different times during the pandemic, they may be in lockdown, isolating or shielding. They will be spending more time within their home living setting, as they will not be attending education, work, respite or other activities, and this may be perceived as a positive experience for the person, with families and staff spending more time undertaking care, support and activities.

Family members, friends, carers and staff are being extremely resourceful and supporting people with learning/intellectual disabilities to do a range of home/ward-based activities. Active support and the proactive part of positive behaviour support are clearly in evidence.

GUIDANCE

Some people with learning/intellectual disabilities are taking the initiative with domestic chores and are learning many new skills. Some are leading the way with the mastery of social media and digital communication and are having an increased amount of social contact. Communal games, quizzes, meal-making and other activities have been developed.

Increased contact with health and social care professionals and volunteers through phone or video link are being appreciated, especially for those who are living alone.

The Covid-19 rules about going out for exercise have had reasonable adjustments for people with 'medical need' (including people with learning disabilities or autism). Families and staff need to ensure that they follow guidance as it is amended during the different phases of the Coronavirus pandemic.

This opportunity, in the face of the lack of the usual structure, means that people may be taking more physical exercise than usual with family and other carers which will have a positive impact on physical health and psychological wellbeing.

PRECIPITATING AND MAINTAINING FACTORS

People with learning/intellectual disabilities with lived experience of trauma and/or pre-existing psychological distress and troubling behaviour are likely to have their stress exacerbated by the Covid-19 situation.

The restrictions may lead to more people with learning/intellectual disabilities experiencing psychological distress for the first time given the degree of constant threat. Depending on an individual's capacity to understand what is happening and opportunities (as indicated above), the sudden and ongoing restrictions may be confusing, anxiety-provoking and frustrating. Routines may be significantly disrupted. The physical environment may be cramped, especially if more family members and friends have congregated for lockdown. In supported living or residential care, other co-tenants/residents are together for more time than is usually the case in a typical week. Visiting to and by friends and family is currently prohibited. As the pandemic lessens this may change in line with government guidance.

The use of personal protective equipment (PPE) within social care settings may be unsettling, reducing successful communication and indeed evoke PTSD responses from previous health care experiences. Staff and families can help to address this using social stories, easy read information and videos that have been produced to help explain this to people, and to give people time to cope with the anxiety and feelings that may be evident.

For patients in assessment and treatment and forensic inpatient units, their circumstances may be particularly challenging. As a consequence of the pandemic, usual trips out or visits from family members are curtailed, alongside the postponement of planned transitions home or to elsewhere in the community.

Attachment relationships may not be positive nor secure. Family or friends who are shielding, self-isolating elsewhere or are unwell will be missed. This may mean increased use of unfamiliar staff/carers (agency etc, due to staff themselves being absent for a variety of Covid-19 related reasons). There may be misunderstandings about why usual family, friends, staff and carers cannot be seen face-to-face. Contact with health and social care professionals by phone or video link may not be understood/appreciated – especially if the individual is not (well) known or if the person's sensory or other needs preclude the use of such media. Professionals will need to be sensitive to issues of capacity to consent and of confidentiality in using video links in situations where the person needs the support of family or staff to be able to use it.

Bereavement associated with Covid-19 may be experienced about co-tenants, family members, staff and significant others. Distress may be felt about adored celebrities. Some of these issues may not come to light until lockdown is reduced, for example, when people return to their day and leisure settings and find out that people they have known for many years have died.

People with learning/intellectual disabilities may have a range of concerns and anxieties. These may include worries about shopping, obtaining food and sufficient medication or other health related or personal care supplies. Some people may have significant worries about their finances both in the short and long term.

People with learning/intellectual disabilities may have greater worries about their own health and that of significant others. Some people will be overly concerned that they may have Covid-19 because of the constant news about the virus, even when they do not have the symptoms. This may be helped as testing becomes more widely available. In addition, they, and their families and staff may not respond to symptoms and signs of illness through fear of catching the virus at the GP or hospital. It is important that the person is supported to talk about any health symptoms, and that families and staff take action by contacting health professionals to ensure that other illnesses/issues are not missed.

Secondary impacts of not going out through fear of infection or the absence of other positive motivators (e.g. to go to college or the shops) may mean increased sedentary behaviour. Limited physical exercise may have adverse long-term impact on the person's physical and mental health. There may be increased use of food, alcohol or smoking to combat stress and provide comfort.

Those with routine interests associated with the media may begin to miss their usual soaps or other programmes (as the schedule runs out of new programmes as they are not able to be made).

Some people may have moved accommodation only recently. They may not have had time to completely adjust to the new setting and build secure attachments with new carers. People may not have had the opportunity for a more gradual transition or to have visits to/from family to help support the change.

People with learning/intellectual disabilities may show signs of psychological distress. This may be evidenced as anger, frustration, anxiety and grief which may be take the form of verbal or physical aggression to themselves or others or to property. People may be at risk of admission to an inpatient unit because of their behaviour.

The tolerance of co-tenants, co-residents, family, carers and staff will be lower than usual due to their constant experience of threat. The potential for domestic abuse must not be underestimated. For people living on their own, loneliness will increase at a time when statutory support may be reduced leaving people feeling anxious, stressed and at risk of depression and other psychological issues.

People with learning/intellectual disabilities who live in residential care homes or shared supported living environments are more at risk of contracting Covid-19 than those in lockdown alone. Many people with learning/intellectual disabilities are at higher risk of serious complications because of pre-existing medical conditions. The experience of hospitalisation for people with learning/intellectual disabilities because of Covid-19 may be more difficult than for others, with staff wearing PPE and restrictions on family or other carers being present.

PSYCHOLOGICAL INTERVENTIONS/ACTIONS

Psychologists will be continuing to offer psychological services to people with learning/intellectual disabilities throughout the Covid-19 pandemic, prioritising people with the greatest needs. These may be different in format to those that they usually undertake, depending on the restrictions in place at any specific time. Depending on the person's needs and abilities, this contact may be by phone or video, text or email, directly with the person, jointly with family members or staff, or via support to the family or staff. The support may also include giving people access to easy read material, social stories and videos that address specific issues related to Covid-19.

Psychologists can:

- 1 Advise on positive behaviour support strategies including how to engage in activities, keeping a routine, making a plan to keep 'mentally healthy'.
- 2 Offer psychological and emotional support especially on coping with anxiety, serious illness, death and bereavement to help both the family and the person.
- 3 Help people with learning disabilities understand and have realistic expectations of themselves and people who support them.
- 4 Develop and share resources for people with learning disabilities, their families and staff.
- 5 Advise about assessment of capacity concerning health-related decisions.
- 6 Ensure that within the restrictions, the least restrictive option is still maintained and ensure minimum disruption to the person and their family.
- 7 Work with the person's network to ensure effective care co-ordination and contact is maintained, and focus where needed on advance care planning and end-of-life support.

Psychologists will continue to offer assessments where needed, but these may be more limited as times during the pandemic whilst virtual contact and social distancing is in place. This may include parts of assessments of intellectual functioning, for dementia and other issues. Psychologists will highlight in their reports where assessments are not as comprehensive as usual, and therefore the limitations of any findings and how they should be interpreted.

Psychologists will work with families and staff to offer them support during the Covid-19 pandemic. This may include education, training and psychological support. Staff and families may need additional support to implement positive behaviour support approaches, understand the impact of the restrictions on the person and themselves, deal with issues of bereavement, isolation, lack of routine and activities, and the impact on themselves and the person leading to trauma responses. This may be through individual consultations, reflective practice groups, provision of information through leaflets and video, and access to apps and other websites.

RECOVERY/TRANSFORMATION PHASE

It is unclear when and how the restrictions will be lifted and the uncertainty can be an additional issue for people with learning/intellectual disabilities. Each individual, their families and staff will have their own coping strategies, with some people being more resilient than others.

One of the most important issues during the recovery/transformation phase will be ensuring that the messages from the government are translated clearly so that people with learning/intellectual disabilities understand what is required of them. Most people with learning/intellectual disabilities do not have a concept of timescale – so will have difficulties in relating to how long it may be until lockdown and other restrictions change for them. Further resources will be developed as the pandemic situation changes.

During the recovery/transformation phase, it will be important to review with the person where possible, and with families and staff, their previous schedule. Lockdown may have changed what people want to engage in after the restrictions are lifted and indeed what is possible. As for all of us, people with learning/intellectual disabilities may want a ‘new normal’ that incorporates a different range of activities and interests for the future.

Psychologists will continue to offer the range of psychological support outlined in the Interventions section above, with the aim of reintroducing face-to-face contact when permitted.

RESOURCES

Many resources have been developed both by national and local organisations to support people with learning/intellectual disabilities and their families and staff. Resources can be used to inform and therefore have an educative function, or to support the psychological needs of the person and their families and staff.

1. Government information on Covid-19

The government website has the latest Covid-19 guidance. It is frequently being updated and the links change:

[Coronavrius FAQ](#)

[Covid-19 changes to the care act](#)

2. Roles of psychologists and other professionals

The UK Learning Disabilities Professional Senate has produced a [paper](#) outlining the role of professions during the Covid-19 pandemic. This was contributed to by members of the Division of Clinical Psychology Faculty for People with Intellectual Disabilities.

3. Trauma Informed Care

Care for people with learning/intellectual disabilities and their families and staff needs to be both trauma and resiliency informed. The Learning Disability Professional Senate guidance on trauma informed care can be found [here](#).

4. Guidance on rights

Guidance on the rights of people with disabilities can be found [here](#).

5. Resources for families and staff

There are a huge range of resources developed specifically for families and staff of people with learning/intellectual disabilities. Most of the learning/intellectual disabilities organisations have produced resources, including:

[Challenging Behaviour Foundation](#)

[Mencap](#)

[Learning Disabilities Professional Senate](#)

[Carers UK](#)

[BILD](#).

6. Easy read/self-help resources for people with learning/intellectual disabilities

Many organisations have worked swiftly to produce information in an easy readily available format to address the information and psychological needs of people with learning disabilities as a result of the Covid-19 crisis. The resources are constantly being updated as the pandemic progresses.

[Public Health England](#)

[The UK LD Professional Senate: Resources to use with people with learning disabilities through the Coronavirus restrictions](#)

[The UK LD Professional Senate: Covid-19: Activity Ideas for people with learning disabilities in in-patient units whilst in isolation](#)

Surrey and Borders Partnership NHS Foundation Trust has developed a series of videos for people with learning disabilities and some for families/staff. The links to the videos and the playlist are as follows:

- [Explaining coronavirus for people with learning disabilities](#)
- [Explaining social distancing for people with learning disabilities](#)
- [Anxiety and the body](#)
- [Five things to do when feeling anxious](#)
- [Five seconds breathing exercise](#)
- [Balloon breathing exercise](#)
- [Breathing exercise using your imagination](#)
- [Explaining mindfulness and the five things exercise](#)
- [My relaxing place exercise](#)
- [Playlist](#).

The Scottish Commission for People with Learning Disabilities published a series of booklets to give people with learning disabilities an opportunity to talk through their feelings with people providing support to them. Each booklet has an accompanying guide for carers/supporters. These are online and print versions that can be ordered [here](#).

The titles so far (each including a guide) are:

- Introduction to Coronavirus
- Feeling down
- Getting a good night's sleep
- Being active and staying well: You can do it! Being active and keeping better
- Solving problems: 'Sort it out' – a way to help you solve your problems booklet
- Coping with anxiety: Feeling anxious about Coronavirus
- Relaxing: A video relaxation exercise (coming soon).

NHS Scotland

Guidance including about Covid-19 in relation to pregnancy and having a baby:

Achieve together

Beyond Words Charity: has produced a series of free books

Purple All Stars: video showing good handwashing

Sensory Integration Education: Hand washing tips for people with sensory difficulties

Cruse have produced easy read information on bereavement:

Death talk

Grieving for people you did not know in person

CONTRIBUTORS

Dr Judith Samuel

Vice Chair DCP FPID.

Dr Karen Dodd

Committee member FPID and Co-Chair of the National Learning Disabilities Professional Senate.

With thanks for contributions of links from members of the DCP FPID committee.



the british
psychological society
promoting excellence in psychology

St Andrews House,
48 Princess Road East,
Leicester LE1 7DR, UK

☎ 0116 254 9568 🌐 www.bps.org.uk ✉ info@bps.org.uk