

SUPPORTING PEOPLE WITH COGNITIVE IMPAIRMENTS (INCLUDING THOSE WITH BEHAVIOUR SUPPORT NEEDS) DURING COVID-19 – ALTERED SERVICE ARRANGEMENTS – MARCH 2020

GENERAL GUIDELINES

As the lives of all Australians are challenged by the on-going COVID-19 crisis, the impact for people with a disability, particularly those with cognitive impairments and/or behaviour support needs, will be felt more than most.

With varied understanding of the situation, major changes to established routines, limited access to family and friends, and potentially new and unfamiliar staff supporting them, many people with cognitive impairments and/or behaviour support needs, are likely to need additional support.

The suggestions in these general guidelines are exactly that – general. Those that know the person with disability best – family, friends and familiar professional and support staff, will be best placed to develop individualised and tailored support responses. If the person has a behaviour support practitioner, support coordinator or medical or allied health therapists and/or family, they may be contacted for support and advice as required.

Most behaviour support providers will be employing alternative means of maintaining contact and providing support to participants and their formal and informal support networks during this period of altered service arrangements (or possibly, a 'lockdown' situation in the future).

It is the hope of Prag Consulting that the information contained in these guidelines will prompt discussion and planning and provide suggestions for supporting people in these uncertain times.

1. Coping with uncertainty and managing anxiety

- **Provide information adjusted to the person's level of understanding** and in a way that best meets the person's communication needs. For example, simple, clear information for those who have verbal communication skills, and alternative methods such as visual communication tools (such as pictures/symbols) for others. For some adults and children with adequate verbal comprehension, Social Stories¹ may be appropriate. You can see examples and free templates for Social Stories by opening the link: <https://www.autismspeaks.org/templates-personalized-teaching-stories>
- **Reframe the issue not as a crisis and look for opportunities** for learning and development. This is also likely to assist in managing anxiety levels. For example, explore new interests and opportunities for skill development; consider things that haven't been possible in the past and extending skills; for example, personal care skills/independent living skills within the home, coping and relaxation skills etc.
- **Observe the person's general moods and behaviour**; invite the person to discuss any issues that might be worrying him/her; validate how the person says they feel and provide reassurance and support (for example, "I can see you're a bit anxious ... It is OK to feel a bit anxious when things change... We can talk about what we can do to make you feel less anxious... should we do that now?" etc.).
- **Identify alternative ways to meet the person's needs, wants and goals**. For example, for those whose day services have closed down, think about the person's interests and strengths. Talk to them about their interests and strengths and consider alternative activities that would provide meaningful engagement. This might be within the home or in 'safe' outdoor/community settings (such as parks, walking tracks, beach, nature reserves). Consider cooking, physical activities/exercise, art and craft, board games, household tasks that the person enjoys, gardening, listening to music/singing, new relaxation activities etc.

¹ <https://carolgraysocialstories.com/social-stories/what-is-it/>

- If the person is non-verbal and/or has more complex needs, and is known to have difficulty coping with a change in routine (such as going out to a particular café), plan alternative 'safe' activities that could be undertaken in the community that the person is known to enjoy. This might be similar to a holiday period during which day programs close, and alternative recreational activities are provided.
- **Maintain structure and develop a new timetable.** Supporting the person to maintain structure in their day and develop a timetable to include alternative activities will offer some predictability and a sense of control. Endless hours in front of the television and altered sleep/wake cycles and disrupted mealtime routines will likely increase anxiety and potentially lead to behavioral challenges.
- **Identify things that could lead to increased anxiety and ways to manage these.** For example, continuous exposure to information (through constant news bulletins) may cause or increase anxiety. Discourage over-engagement in watching television or use of social media by offering alternative activities. Provide positive feedback for successful redirection.

2. Maintaining social and emotional connectedness with families and friends, and ties with formal support providers

- **Explore alternative means of maintaining connections;** for example, substituting visits by family or friends with a Face Time call; use of phone calls, Skype chats/other video calls etc. Schedule these into the person's timetable/daily structure and ensure they happen as planned.
- **Ensure connections with family, friends and formal supports** the person might wish to see or speak to are maintained through these alternative means, particularly where regular visits by family/friends or others have been restricted.
- **Check in with people regularly, and ensure you maintain social interactions;** activities (such as suggested above) are a great way to ensure people feel connected and contented and provide a sense of purpose. Consider 'group chat' mechanisms (such as Zoom) to bring people together at a regular time each week. For example, is it possible for the Tuesday morning coffee group to happen virtually?

- ***Spend as much 'quality time' as possible with the people you support***, as opposed to time engaged in other tasks (for example, completing non-essential documentation). Consider changes to daily routines and organisational reporting/compliance activities to enable maximum and meaningful engagement between people and support staff.

3. Supporting people during challenging times

- As we all know, stressful times can lead to behavioral expressions that may be challenging. At such times, it is essential to maintain the same support principles that our usual responses would be based on during behavioral crises). For example:
 - Monitoring for known early 'warning signs' of anxiety, agitation or behavioral escalation;
 - Offering supportive redirection (for example, calming activities or activities the person enjoys) at these early signs of anxiety, agitation or behavioral escalation;
 - Staying calm and neutral and addressing the person's concerns or anxieties as they present;
 - At all times, respecting people's fears and anxieties, and providing supportive responses (for example, listening to and validating the person's concerns/needs; providing reassurance; and identifying ways to meet/resolve the need); and
 - Ensuring time to debrief and to teach better adaptive behaviour/responses only when the person is ready and/or wants to debrief (that is, never during a behavioral episode or even immediately afterwards).
- Where people have current behaviour support plans or documented response/support strategies, they might need to be reviewed or adapted to the current/new situation as required. This might need consultation with others who know the person well, including families, other staff/peers, behaviour support practitioners or other therapists.