

Advice from the Social Care Institute for Excellence

COVID-19 guide for carers and family supporting adults and children with learning disabilities or autistic adults and children

Updated: 17 April 2020 (next version expected 23 April 2020)

This is a guide to help family members and carers supporting adults and children with learning disabilities or an autistic adult or child through the COVID-19 crisis. Its aim is to ensure that carers are able to carry on giving good, safe support to their family members during the pandemic.

Autistic people and people with learning disabilities enjoy the same human rights as the rest of the population, and families play an important role in promoting and upholding these rights, so that autistic people and people with learning disabilities can enjoy lives that are rich, fulfilling and fully included in society.

During the COVID-19 pandemic, however, everyone's lives are being limited, and everyone is having to make changes to the way we live together and in communities, to combat the virus. This guidance aims to help families keep people with learning disabilities and/or autism safe, and to help them play their part in getting through this national emergency, while at the same time protecting and promoting their quality of life wherever possible.

SCIE, working with senior social care leaders and sector partners, will update these guides weekly.

This public health crisis is likely to have an acute impact on those with care and support needs, carers and staff. The care and help available may be limited compared with usual provision, because more people are needing assistance, and staff may be ill or self-isolating. Autistic people and people with learning disabilities are likely to be worried about their own health, and that of their loved ones, while also having routines interrupted, and access to friends or colleagues halted. Those providing support to them will be concerned about their own and their family's health too, and may be facing knock-on effects of the pandemic such as lost income or jobs. Family members may be spending more time in the immediate company of the person with learning disabilities than they have done for some time.

Helping the person to understand the change

The current health crisis has increased confusion, fear and anxiety for everyone, and inevitably it will bring additional challenges when supporting autistic people and people with learning disabilities. There may be a need for more considered solutions if people are used to specific routines, such as going to college or school, and are unsettled by change.

Each person is an individual, as family carers recognise better than anyone. It is important therefore to think about what your family member enjoys normally, what strategies and plans typically work when things are not going well, and to continue to provide calm and reassuring support.

Much has been changed by the coronavirus, but the personality, preferences and interests of your family member will likely not have done. So make sure they are included in discussions and decisions, so they'll have the best chance of understanding what is going on, and of staying in control of their lives as much as possible.

It may help to think about what strategies have been used before if the person was going, for example, on holiday or to hospital.

- Emphasise the things that can remain normal.
- Encourage the establishing of daily routines, including exercise, social contact, and good sleep routines.
- Consistency: who normally supports the person with particular tasks? Is it possible to maintain that or keep in contact in some way?
- Try to explain in simple terms why things are changing. e.g. there is a virus that might make us ill so we are trying to keep safe.
- Explain that the restrictions are not forever – we can go back to normal when the danger has passed.
- Use accessible resources from organisations such as [Learning Disabilities England](#), and the [National Autistic Society](#).
- Can you keep a list of all the things the person wants to do once restrictions are lifted, so the person can see these have not been forgotten?
- Is there anything that helps to calm the person that can help e.g. listening to music, gardening or baking?
- The World Health Organisation (WHO) recommends that people have at least one form of exercise daily. Plan with the person taking a daily walk or run.

The [Royal College of Occupational Therapists has useful guidance](#)