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

Updated: 19 January 2022

This is a guide to help family members and carers living with and supporting adults and children with learning disabilities, or an autistic adult or child, through the COVID-19 pandemic. Its aim is to assist carers to carry on giving good, safe support to their family members during the pandemic. The guide focuses on families who are living with an autistic person or a person with learning disabilities; if your family member lives away from the family home, you may also wish to look at our guide for care staff. The government has also published guidance for families supporting adults.

People with learning disabilities and autistic people enjoy the same human rights as the rest of the population. 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. Local authorities are still expected to take all reasonable steps to continue to meet people’s eligible care and support needs, and the support needs of carers. Social care is underpinned by human rights, and this has not changed. During the COVID-19 pandemic, however, everyone’s lives have been limited, and everyone has had to make changes to the way we live together and within communities to combat the virus. The virus is still circulating at a high rate and lives will continue to be affected.

The pandemic has had an acute impact on those with care and support needs, carers and staff. The care and help available may be limited at times compared with usual provision, because 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 if anyone needs to isolate.
Helping the person to understand the changes

The pandemic has increased confusion, fear and anxiety for everyone, and inevitably it will continue to bring additional challenges when supporting autistic people and people with learning disabilities. This may include the requirement to self-isolate if the person develops symptoms or has not yet been fully vaccinated and has been in close contact with someone who tests positive. In such situations there may be a need for detailed planning if people are used to specific routines 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 happening, and of staying in control of their lives as much as possible.

If there is a need to isolate or services need to close for a short time, 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 those things that can remain normal.
- Encourage the establishing of different 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? If not, how can this be explained?
- Try to explain in simple terms why things need to be different for a time. 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 risk has passed.
- Use accessible resources from organisations such as Learning Disabilities England link 3, the National Autistic Society link 4 and Books Beyond Words link 5.
- Can you keep a list of all the things the person wants to do once it is possible, 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 following resource may also be helpful:

- Explaining Coronavirus for People with Learning Disabilities and other videos link 6 (Surrey and Borders Partnership Trust)

Severe learning disability and behaviour that challenges
If the person in your family has a severe learning disability or exhibits behaviour that challenges this may be a particularly difficult time. The Challenging Behaviour Foundation have put together a range of information and resources for families and carers of people with severe learning disabilities and/or behaviour that challenges. This includes some advice on what you might do if challenging behaviour escalates at this time, and some information on coronavirus and the law.

General measures and going out

As the coronavirus is still in general circulation and a new variant is spreading rapidly, we need to continue to minimise the chances of catching and spreading COVID-19.

In light of the ongoing spread of COVID-19 and new variants of concern, some legal restrictions have been re-introduced. Everyone must:

- Wear a face covering in most indoor settings and on public transport
- Get tested if you develop any symptoms
- Isolate if you have a positive test or if you are contacted by NHS Test and Trace and haven’t yet been fully vaccinated

Everyone is advised to:

- Wear a face covering in other crowded areas
- Work from home if it is possible to do so
- Stay outdoors when mixing with others or let fresh air in if mixing indoors
- Minimise the number of people you mix with and for how long
- Wash your hands or use hand sanitiser regularly through the day
- Take a lateral flow test before visiting people at higher risk of severe illness or before visiting crowded and enclosed spaces
- Consider asymptomatic testing to help manage your personal risk
- Try to stay at home if you are feeling unwell.

It is currently compulsory in England to wear a face mask on public transport and in most indoor settings. However, there will still be exceptions, including for people who need to lip read, and if wearing a mask might cause someone severe distress. The Government has produced some cards and badges which you can carry to explain why you cannot wear a face mask. Jane Green and SEDS have also produced some exception cards, too.

Many people are now fully vaccinated and a booster jab is being offered to all adults who had their second jab at least three months ago. However, even when a person has had both doses, it remains vital that they continue to follow the measures outlined in this guide.

People who have received both their vaccines at least two weeks ago and those aged under 18 years and six months are no longer required to self-isolate if they...
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People in Wales link 12, Scotland link 13 and Northern Ireland link 14 should follow the guidance specific to their country.

If the family member you are supporting has to isolate, or cannot attend their usual day time activities, some organisations have come up with indoor activities which people may enjoy:

- Resources to help with structure and keeping busy link 15 (Mencap)
- Visual supports resource pack for parents and carers link 16 (NHS, Hounslow and Richmond Community Healthcare)
- Keeping busy at home: Activities for parents and carers link 17 (NHS, Hounslow and Richmond Community Healthcare)

Local authorities and the NHS have developed teams of staff and volunteers to support people who need additional support during this time. You can find local support groups via Covid 19 Mutual Aid UK link 18. There may also be other local groups, locatable via social media such as WhatsApp or Facebook, where people can find support, and neighbours willing to help out. It is a good idea to approach your local authority, who are strategically supporting these groups, so you can access safe, appropriate support.

Maintaining relationships

It is important that people are supported to maintain their relationships with family, friends and partners.

Restrictions on the number of people who can meet indoors and outdoors have been lifted, as has the requirement to remain 2m from anyone you don’t live with. However, as the infection rate is currently high, everyone is advised to be cautious and to take the actions that are known to reduce the chance of spreading COVID-19:

- Meet outside
- If meeting inside, keep the space well ventilated
- Minimise how many people are in close contact and for how long
- Wash hands and clean surfaces regularly
- Take the vaccine when offered it
- Remember that some people are more vulnerable than others to being seriously ill with COVID-19
- Get tested twice a week

Anyone living in an area where there is known to be spread of a new variant or where extra support is being provided due to very high numbers of infections should be particularly cautious.

Autistic people and people with learning disabilities have made use, like the rest of the population, of various video call facilities and other ways to keep in touch with friends, colleagues and loved ones, and this should continue to be supported wherever it is what the person wants. Learning Disability England have a range of resources to help people stay connected, including an easy read guide to using WhatsApp. Find the system which works best for each person you support.

Even as restrictions ease, remember that your loved ones may continue to experience loneliness as a result of the changes in their life. They may also experience anxiety about the virus outbreak and about beginning to mix more freely again. Some useful resources to support them are:

- 10 tips to help you if you are worried about coronavirus (NHS)
- Coronavirus: Information from other organisations (Mencap)
- Explaining Coronavirus for People with Learning Disabilities and other videos (Surrey and Borders Partnership Trust)

Children and young people

Attending schools and colleges

Updated guidance for schools and colleges supporting children and young people with SEND has been issued. Schools and colleges are open, enabling children and young people to continue with face-to-face education. Remote learning should be provided for any children and young people who have to remain at home because they are self-isolating.

Personal budgets and access to respite care

For children and young people with an EHC plan, the duties relating to personal budgets remain in place. A child’s parent, or a young person, has a right to request a personal budget when the local authority has completed an education health and care needs assessment and confirmed that it will prepare an EHC plan. They may also request a personal budget during a statutory review of an existing EHC plan.

Services for disabled children provided under section 17 of the Children Act 1989 typically include short breaks for parent carers. The local authority remains under a duty to provide these in appropriate circumstances. The Government recognises that this is likely to prove challenging during the coronavirus (COVID-19) outbreak, but is asking local authorities to ensure every effort is made to continue to provide this kind of important support for families who need it, wherever possible.

Where it is not possible for local authorities to arrange respite care for families as a result of the coronavirus outbreak, the Government encourages parents, carers and young...
people to discuss this with their local authority and agree what alternative arrangements can be made. This could include, for example, local authorities considering whether making a personal budget available on a temporary basis may enable the family to secure alternative respite care arrangements.

Further reading

- Actions for schools during coronavirus  link 25  (Department for Education)
- Supporting children and young people with SEND as schools and colleges prepare for wider opening (Department for Education)  link 26

Further support and advice for families of children and young people with learning disabilities and autistic children and young people.

The Council for Disabled Children has a page of advice and information  link 27  including answers to frequently asked questions by families.

Contact  link 28  offer case work, information and advice for families with disabled children.

Staying well

Many local testing sites are now offering asymptomatic testing for all members of the public, and the option of twice-weekly lateral flow testing at home is also available for everyone. If you have a positive lateral flow test with no symptoms, it is not currently necessary to take a confirmatory PCR test. You should just isolate for the required period.

Infection control and good personal hygiene

One of the most important things that families can do during the pandemic is to ensure as much as possible that the person with learning disabilities or autistic person with whom they live is maintaining good personal hygiene and household cleanliness, to reduce the risk of catching or spreading the infection. Perhaps especially for autistic people, the changes of routine involved may cause some distress.

Do:

- ✔ Wash your hands with soap and water often – do this for at least 20 seconds.
- ✔ Use hand sanitiser gel if soap and water are not available.
- ✔ Wash your hands as soon as you get home.
- ✔ Cover your mouth and nose with a tissue or your sleeve (not your hands) when you cough or sneeze.
- ✔ Put used tissues in the bin immediately and wash your hands afterwards.

Do not:

X Touch your eyes, nose or mouth if your hands are not clean.

Supporting people with personal hygiene and cleanliness around the house

- The autistic person or person with a learning disability in your family may want to do as much for themselves as possible. Everything they can do for themselves safely and effectively, they should do.
- Some people, conversely, will not want to engage with personal hygiene routines. Explaining the risks, and stressing the importance of good hygiene may help, but will sometimes be challenging. See our section on Not sticking to the guidelines link 29.
- There may be tasks that you have usually done hands-on with your family member – such as tooth-brushing - where prompting may be possible.
- People will need to wash their hands more often, and for longer, than they might do normally: for at least 20 seconds every two hours. The need for this has to be explained, and any skin care issues arising from it addressed.
- Cleaning of the house should be done regularly and thoroughly, especially in shared areas.
- Wipe surfaces that are touched regularly with household disinfectant.

Here are some other sources of information on cleaning and infection control which may be helpful:

- Government guidance link 31 for unpaid workers
- Cleaning non-healthcare settings Public Health England link 32
- Healthcare settings Public Health England link 33
- Residential care Public Health England link 34, (Skills for Care) link 35
- Guidance on supported living services - Supported living services during coronavirus (COVID-19) - GOV.UK (www.gov.uk) link 37
- NICE / SCIE guidance for residential care link 38

What to do if you or the person you care for has symptoms

The government provides guidance link 39 for anyone caring for friends and family members, including advice on what to do if you or the person that you care for has symptoms of COVID-19.

It is important to note that the guidance differs depending on whether you, the person you support, or anyone else in the household is in the clinically vulnerable group (who are at increased risk of severe illness from coronavirus) or the clinically extremely vulnerable (shielded) group (who are at greatest risk of severe illness from coronavirus). The advice relating to each group is summarised below.
If nobody in the family, including the family member who is an autistic person or has learning disabilities, is ill or thought to have symptoms, then support can continue in the usual way.

If someone in the household does have symptoms or confirmed coronavirus then government advice on what to do depends on whether it is the person with learning disabilities or autistic person who has symptoms, or you as carer or another member of the household. From 16 August, what to do is also dependant on whether or not people have had both vaccines.

**Everyone must continue to self-isolate if they develop symptoms or test positive.**

Anyone who tests positive must isolate for a period of 10 full days. It may be possible to end your period of isolation early if:

- you have two negative lateral flow tests
- the lateral flow tests are taken 24 hours apart and not before day 5 of your period of isolation
- you do not have a high temperature.

If all these conditions are met, you can end your isolation after the second negative lateral flow test. You are strongly advised to follow all the general measures outlined above for the remainder of the 10-day period.

Adults who have been fully vaccinated at least two weeks previously, and those aged under 18 years and six months, are no longer required to isolate if they are a close contact of someone who tests positive. Instead, you will be advised to:

- take a lateral flow test every day for seven days
- take this daily lateral flow test before leaving home for the first time that day
- immediately self-isolate if any of these tests are positive.

You should also consider the following steps to help prevent the spread of COVID-19:

- Limiting close contact outside your household, particularly in enclosed spaces
- Wearing a face covering in enclosed spaces and where it isn't possible to keep your distance, even if it isn't required by law
- Limiting contact with anyone who is very vulnerable
- Taking part in regular lateral flow testing

**Where people have not yet been fully vaccinated, the advice below still applies.**

If the person you care for has symptoms and you are not clinically extremely vulnerable

| If someone in your household has symptoms you should follow the Stay at home guidance which states that the first person in the household to have symptoms of coronavirus, must stay at home for ten days. | 8/20 |

It may be possible to end the period of isolation early if:

- the person has two negative lateral flow tests
- the lateral flow tests are taken 24 hours apart and not before day 5 of the period of isolation
- the person does not have a high temperature.

If all these conditions are met, the period of isolation can end after the second negative lateral flow test. The person is strongly advised to follow all the general measures outlined above for the remainder of the 10-day period.

All other household members who remain well but who are not fully vaccinated must stay at home and not leave the house for 10 days.

However, the guidance for carers acknowledges that following the Stay at Home guidance may not be easy to achieve where you provide close contact care, such as washing and bathing.

If you and other family members do not fall into the clinically ‘vulnerable group’ or the clinically ‘extremely vulnerable group’ you can continue to provide care. You should take additional precautions where possible.

- The person should self-isolate as best they can within the family home for ten days – staying in their own room, and using a separate bathroom if that is possible.
- Their use of shared spaces – such as sitting rooms – should be minimised. Sometimes this just will not be possible, which adds to the challenge.
- Extra attention to cleaning and personal hygiene may lessen the risks.
- Avoid sharing towels.
- Try to keep laundry separate.
- Avoid shaking bedding.

You could also consider using facemasks if the infected person is moving around the home.

If the person you care for has symptoms and you are in the clinically extremely vulnerable group

If you are in the **clinically extremely vulnerable group** link 41 you should strictly avoid contact with someone who is displaying symptoms of coronavirus (COVID-19).

Where possible, ask friends and family who can support you in providing care for their help. You should distance yourself from the person you care for as much as possible.

If you cannot organise alternative care you can contact your **local authority** link 42 or **health care provider** link 43. If you do not know how to do this you can contact NHS 111. It may also be helpful to contact your local carers support organisation. You can find out about local carer organisations at **Carers UK** link 44.
If someone in your household has symptoms you should follow the Stay at home guidance which states that the first person in the household to have symptoms of coronavirus, must stay at home for ten days.

It may be possible to end the period of isolation early if:

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All other household members who remain well but are not fully vaccinated must stay at home and not leave the house for 10 days.

However, the guidance for carers acknowledges that following the Stay at Home guidance may not be easy to achieve where you provide close contact care, such as washing and bathing.

If you care for a person in a clinically ‘vulnerable group’, you should self-isolate as best as possible within the home, and make alternative arrangements for their care with family members and friends. If you cannot organise alternative care you can contact your local authority or NHS trust.

If you care for a person in a clinically ‘extremely vulnerable group’, you should strictly avoid contact with the person you care for and, where possible, ask friends and family who can support you for help in providing care. You should distance yourself from the person you care for as much as possible and follow the guidance for protecting people who are clinically extremely vulnerable from COVID-19.

If you cannot organise alternative care you can contact your local authority or health care provider. If you do not know how to do this, you can contact NHS 111. It may also be helpful to contact your local carers support organisation. You can find out about local carer organisations at Carers UK.

If a care worker or personal assistant who would normally visit the home has symptoms (a new continuous cough or fever or loss/change in your sense of smell or taste)
They should stay away, self-isolate in their own home and get a test. If they test negative they can return to providing support.

Most health and social care staff have been fully vaccinated, and many have had their booster. On 11 November 2021 it became mandatory for anyone working in a care home to be fully vaccinated unless exempt. From April 2022 it will also be mandatory for all frontline health and social care staff to be fully vaccinated unless exempt.

**Personal budgets and personal assistants**

**Weekly COVID-19 testing is now available for personal assistants** link 52

If the person with learning disabilities or autistic person in your family uses a personal budget to employ a personal assistant (PA) you should review the support arrangements that are in place for when the PA is unable to work due to sickness or annual leave. You should consider if these arrangements are robust enough should a personal assistant need to self-isolate because they are ill themselves, are in a vulnerable group or, if they are not yet fully vaccinated, live in a household where someone has developed symptoms of COVID-19.

The next section provides general advice on **contingency planning** link 53, and the government have provided further advice specific for people who employ their PA.

Should you find yourself in a position where your personal assistant is unable to support you due to self-isolation or contraction of COVID-19 and you have no alternative arrangements available to you, you should contact the adult social care team or CCG team that provides your direct payment for alternative care arrangements. These teams must have systems and processes in place to respond to you as quickly as possible, acknowledging the nature of your needs and circumstance, and should support you to make suitable alternative arrangements.

Personal assistants are eligible for personal protective equipment (PPE) should that be required. If the existing direct payment contains funding to purchase PPE for the PA, you should continue to use that funding to purchase PPE. If you, or your PA, cannot obtain PPE in this way, or your direct payment is not set up to fund PPE, you should ask for assistance from the local authority or CCG that provides your direct payment who should help you to get the PPE you require. The Government has provided further **advice and guidance on PA’s employed via direct payments and PPE** link 54.

If your family member is using a direct payment to buy care and support via a service such as a home care agency, they or you should:

- Make early contact with the agency. Discuss the situation and agree any actions that will be taken should the regular, paid carer be unavailable.
- Ensure that they have your up-to-date details, any relevant care and support plans and relevant dates if you need to attend important appointments with support.
If the direct payment is used to purchase other types of support, it's important that you speak to the provider and agree arrangements if you foresee any issues in delivering this service during this period.

DHSC have provided guidance and a FAQ for people receiving direct payments.

Contingency planning

Many people caring for someone at home will already have plans in place in case someone is unable to continue in their caring role. Usually this will rely on other known support such as other family members, or an agency who can provide cover.

If you are worried that you don't have a plan in place, or your usual contingency plan cannot be implemented because of the current crisis, then you can make a start:

- Talk to your family member – the more they understand what is happening, the more they will take action to keep themselves safe.
- Write down any key contacts (other family, neighbours, friends or professionals) who can be called upon for assistance.
- Make sure that information about the support your family member needs is available, particularly if they would not be able to communicate this for themselves – for example, any information about specific needs, medication or routines.
- Make a note of where you usually get any specialist supplies (e.g. incontinence supplies).
- If you can't think of people who could help, call your local authority adult social care and ask them to advise.

Together Matters has written information to help family carers plan with others, including professional care staff, to get the support they need during the current crisis.

Not following guidance and advice

It may be that your family member is reluctant to follow, or does not understand, the guidance around self-isolation or the advice that can help them to stay well. This can be complex because it increases the risk of infection for themselves and for other people.

- explain, repeatedly if necessary, the reasons behind the new ways of living, using some of the resources listed in this guide
- use whatever communication techniques work best in normal circumstances with your family member
- use positive reinforcement wherever possible to encourage your family member to follow the advice and guidance
- mitigate any risks, such as cleaning surfaces if the person does not wash their hands after a trip out
- contact your local Community Team for Learning Disabilities or specialist autism team for advice.

Taking care of yourself
This is likely to have been a difficult time for you as a family carer as well as for the person that you support. You may continue to experience increased stress due to fear, uncertainty and the reduced formal support available at times, which could result in increased physical and emotional strain.

**Government advice for unpaid carers** [link 57] has a section on looking after your own health while supporting others.

Carers UK has some advice for carers on **protection your mental wellbeing** [link 58].

If you start feeling that you are unable to cope, seek support and advice from your local authority.

**Healthcare**

**Identifying health concerns**

You will know your family member very well. It is important that you use your knowledge of the individual, how they normally are when well, and how they spend their day, to understand if there is any change. This is especially important if the person is unable to express or communicate how they are feeling. Changes may be due to the change in routine, ill health or an impact on their mental wellbeing.

It is important to monitor your family member for any signs of coronavirus – a new continuous cough or fever (equal to or above 37.8°C) or loss/change in your sense of smell or taste. It is also important to be aware that the variants causing most infections currently (known as the Delta and Omicron variants) have some different symptoms – headache, sore throat, runny nose and fever are most commonly reported. If you think that the autistic person or the person with learning disabilities in your family may have significant coronavirus symptoms, follow the procedure to arrange a test, or contact NHS 111, online [link 59] in the first instance, or by phone, for clinical advice.

It is also important to monitor people's general health and any underlying conditions that they may have; other health risks have not gone away. The local community learning disability team will still be operating, and will be available for advice or again, you can contact your GP or 111. You should not be afraid to seek medical care or support for conditions not related to coronavirus, for your family member or yourself.

Autistic people and people with a learning disability have equal rights to access healthcare, but we know that they sometimes experience barriers to getting the healthcare they need. During the coronavirus pandemic it is still the responsibility of the NHS to make reasonable adjustments where needed to allow equal access. Find out more about **reasonable adjustments** [link 60].

All GPs and other health services have received a letter explaining the importance of equal access to healthcare. In particular it clarifies use of the Clinical Frailty Scale (CFS) and the use of do not attempt cardiopulmonary resuscitation (DNACPR) with younger patients with a stable long-term physical need, learning disability or autism. A person should not have:
DNACPR put in place without consultation or just on the basis of having a learning disability or significant levels of social care and support. The NHS provides some further information about available advocacy support and VoiceAbility have some useful information about advocacy during coronavirus.

NHS England have produced two documents for people with learning disabilities and autistic people about accessing NHS services during coronavirus – one in easy read, and one in plain English.

Shielding

Shielding ended on 1 April. People who are considered to be clinically extremely vulnerable are advised to continue to follow current government guidance. Some individuals who are not in the clinically extremely vulnerable group are nonetheless at an increased risk of severe illness from coronavirus:

- anyone aged 70 years or older (regardless of medical conditions)
- anyone aged under 70 years with an underlying health condition – for most this will align with eligibility for the flu jab on medical grounds.

Although age and underlying health conditions are the greatest risk factors, the evidence suggests that other groups are also more likely to become seriously ill. This includes men, people from Black, Asian and minority ethnic (BAME) backgrounds, those living in more deprived areas, those born outside the UK or Ireland, and those living in a care home.

If the person in your family is additionally vulnerable, you should support them to consider what steps they wish to take to minimise the risk of infection. This could include continuing to distance from those they do not live with, and asking friends and family to take a lateral flow test and wear a face covering when visiting indoors.

Going into hospital

In case the person being cared for does need to go into hospital it is worth making sure that their hospital passport is up to date. If you do not already have a hospital passport there is an emergency COVID-19 passport, and a presentation about how to fill it in. Learning Disability England has produced an easy read guide to help support people who may need to go into hospital.

If the person that you support needs to go into hospital because of coronavirus, Mencap has produced some easy read guides to going into hospital which may help explain what will happen.

Further reading

- Alert cards for autistic adults and adults with health needs (Jane Green, InfiniteAutism)
Advance decisions to refuse treatment and advance planning

There has been a great deal of concern during the pandemic that some people - especially people with complex health issues - have been pressured into agreeing to DNACPRs, or that GPs and health professionals may have issued blanket decision across groups of people.

Advance planning and decision making are important tools to make sure people remain in control of their health choices and rights. An advance decision to refuse treatment (ADRT) can be made by anyone with the mental capacity to make their wishes clear, and the person’s wishes must be respected. This may include a decision by the individual to refuse certain types of treatment. This is just as much the case for people with a learning disability or an autistic person as anyone else.

It may be helpful to have a conversation about advance decisions with anyone who has a health condition that may shorten their life, or who is in the high-risk groups that have been identified in relation to COVID-19. This will aim to ensure that your family member remains in control and their wishes are respected.

The charity Compassion in Dying offer advice and a range of resources to help people through the process of making an advance decision to refuse treatment.

The Royal College of Physicians offers a guide, specific to COVID-19, on Understanding treatments and outcomes in hospital and critical care.

The National Institute for Health and Care Excellence provide a range of resources on Decision-making and mental capacity.

Easements of the Care Act 2014 and a framework for decision-making

In March 2020, emergency legislation was introduced to help social care to cope under a possible increase in demand and reduction in staffing. Through the act, there were
implications for children and young adults including changes made to the obligations under the Care Act (2014) and Mental Health Act (1983). This included the removal of the duty of local authorities to carry out a detailed assessment of the needs of young adults, on turning 18 years of age, and their carers when transitioning to adult services.

Since the inclusion of these Care Act easement powers, only eight local authorities have had need to use them and not since 29 June 2020. These easements expired in July 2021 and are no longer in force.

These changes did not affect the Human Rights Act. Local authorities remained under a duty to meet needs where failure to do so would breach an individual's human rights under the European Convention on Human Rights. Duties in the Mental Capacity Act 2005 relating to Deprivation of Liberty Safeguards (DoLS) remained in place, as did duties imposed under the Equality Act 2010. Safeguarding duties were not affected by the easements.

Decisions about care and support should continue to be made in line with the Ethical Framework for Adult Social Care which all local authorities are expected to observe. The ethical framework emphasises eight principles:

- Respect
- Reasonableness
- Minimising harm
- Inclusiveness
- Accountability
- Flexibility
- Proportionality
- Community

Alongside the ethical framework, local authorities should continue to respect the principles of personalisation and co-production which are set out in the Making it Real framework for personalised care and support.

Safeguarding

There are no changes to safeguarding laws or duties. Additional issues may arise for you due to heightened anxiety in the home and any related behaviours. As a family carer you may experience increased stress due to fear, uncertainty and the reduced formal support, which could result in increased physical and emotional strain. This is understandable, and you should do what you can to take care of yourself as well as the person that you support.

Thousands of new volunteers have been drafted in to help. If you have any concerns about volunteers or new people who are coming into contact with you or your family member during this time, you can talk to the local authority about your concerns. See SCIE's Safeguarding adults during the COVID-19 crisis. Similarly, there has already during the pandemic been an increase in fraud and scamming of people with additional...
vulnerabilities, so keep an eye out for this, and support your family member not to be too trusting of strangers offering help, or emails and texts that purport to be official.

### Further reading

- **Coping as carer during coronavirus, a personal take** [link](#) (Carers Trust)
- **Coronavirus: protecting your mental wellbeing** [link](#) (Carers UK)

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## Death and bereavement

The pandemic means there has been a lot of discussion of death in the media, and there continues to be an increased chance that everyone, including autistic people and people with a learning disability, will experience the death of a family member, or friend.

It may be tempting to try and shield people with a learning disability or autistic people from upsetting subjects such as death, but generally this is not helpful. Having open and honest discussions about death is often the best approach, but you will be in the best position to judge how to handle these conversations. It is normally advisable to avoid euphemisms like ‘gone to sleep’ or ‘gone to a better place’, which can cause confusion, especially with someone who may interpret such comments very literally.

Do not be afraid of showing your own emotions while supporting someone through a bereavement. People with learning disabilities can feel supported by seeing that you are upset too.

It may be useful to have conversations about death before people have personal experience of it. Media discussions of deaths due to coronavirus could be a way to start these conversations.

The resources below provide more detailed advice and resources for talking about death and bereavement with people with a learning disability and autistic people.

### Further reading

- **Bereavement and learning disabilities** [link](#) (Cheshire and Wirral Partnerships, NHS)
- **Dealing with a bereavement** [link](#) (Mencap)
- **Loss, bereavement and death** [link](#) (British Institute of Learning Disabilities)
- **Grief after bereavement or loss** [link](#) (NHS)
- **Useful contacts** [link](#) (Bereavement Advice Centre)
- **Breaking Bad News** [link](#)
- **Dying to matter** [link](#) (Dimensions)
- **Your Covid Recovery** [link](#)
SCIE COVID-19 guides

SCIE has produced parallel guides for people providing support to people with learning disabilities and autistic adults:

- A guide for social workers supporting an adult with learning disabilities and autistic adults through the COVID-19 crisis
- A guide for home care staff supporting an adult with learning disabilities and autistic adults through the COVID-19 crisis

link 4 | https://www.autism.org.uk/services/helplines/coronavirus.aspx
link 5 | https://booksbeyonwords.co.uk/coping-with-coronavirus
link 6 | https://www.youtube.com/playlist?list=PLfVgWWNqce45o8XjHncVjCjJjMfU8u_-
link 7 | https://www.challengingbehaviour.org.uk/information/covid19information.html
link 8 | https://www.challengingbehaviour.org.uk/learning-disability-assets/3challengingbehavioursupportingyourlovedoneathome.pdf
link 10 | https://www.gov.uk/government/publications/face-coverings-when-to-wear-one-and-how-to-make-your-own
link 11 | https://www.sussexeds.com/covid-19-1
link 12 | https://gov.wales/coronavirus
link 18 | https://covidmutualaid.org/
link 19 | https://www.learningdisabilityengland.org.uk/coronavirus-hub/how-can-i-stay-connected/
link 23 | https://www.youtube.com/playlist?list=PLfVgWWNqce45o8XjHncVjCjJjMfU8u_-