COVID-19 guide for care staff supporting adults with learning disabilities or autistic adults

Updated: 01 November 2021

This is a guide to help care staff and personal assistants supporting adults with learning disabilities and autistic adults through the COVID-19 pandemic. Its aim is to assist the provision of high-quality care and support.

People with learning disabilities and autistic people have the same rights as the rest of the population to live purposeful lives as active members of families and communities. At its best, social care promotes and upholds these rights, so that people with learning disabilities and autistic people can enjoy lives that are rich, fulfilling and fully included in society. Social care is underpinned by human rights and supported by the Mental Capacity Act – as the legal framework which asserts and supports people’s rights to make their own decisions. 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. Although most legal restrictions have now been lifted, the virus is still circulating at a high rate and lives will continue to be affected.

This public health crisis has had an acute impact on those with care and support needs, carers and staff. Those you support, and their families, may still be worried about their health; their routines could perhaps be significantly interrupted through the need to isolate; and people may have difficulty understanding the changes and ongoing requirements for caution and infection control. All of these issues may continue to cause heightened anxiety.

As a care provider you and your staff may be anxious about your own health and that of your family’s; you may also be under increased work pressure due to other staff being off sick or isolating, and pressures may be exacerbated by people’s usual activities (e.g. day support) being curtailed at times.
This document is aimed at supporting you and enabling you and your colleagues to work as safely and proactively as possible. More detailed guidance is available.

**Helping the person to understand the changes**

Supporting autistic people and people with a learning disability requires skill and time in what can sometimes be complex situations. The pandemic has increased confusion, fear and anxiety for everyone, and inevitably it will continue to bring additional challenges. 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 where people are used to specific routines, and are unsettled by change.

Each person is an individual. It is important therefore to think about what the person you are supporting enjoys normally – how they choose to spend their time, who is important to them, 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 the person you are supporting will likely not have done. So, make sure the person is 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 the person you support does need to change their routine and stay at home for a 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.

- Think about the things that can remain normal and emphasise them.
- 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?
- 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.
- Use accessible resources from organisations such as Learning Disabilities England, the National Autistic Society and Books Beyond Words.
- Negotiate, e.g. if we stay in stay in today, we can do your favourite activity.
- 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** (Surrey and Borders Partnership Trust)

**General measures**
As the coronavirus is still in general circulation, we need to continue to minimise the chances of catching and spreading COVID-19.

Although most legal restrictions have been lifted, there is ongoing spread of COVID-19 and new variants of concern have been identified.

Everyone should continue to:

- Get tested if you develop any symptoms and consider asymptomatic testing to help manage your personal risk
- Isolate if you have a positive test and 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 crowded areas, including public transport
- 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 tests and self-isolate if required
- Try to stay at home if you are feeling unwell

It is no longer compulsory in England to wear a face mask on public transport and in a wide range of indoor settings but it is both advised and likely that many places will ask you to continue to do so. 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 the priority groups. 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 are a close contact of someone who tests positive. They will instead be given advice on testing and guidance on preventing spread of COVID-19.

People in Wales, Scotland and Northern Ireland should follow the guidance specific to their country.

Shielding ended on 1 April. Those in the clinically extremely vulnerable group, and people caring for them, should continue to follow the updated shielding guidance for the foreseeable future.
If the person you are supporting has to isolate, or cannot attend their usual daytime activities, these organisations have produced suggestions for things to do indoors.

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

## 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 has a range of [ideas to help people stay connected](https://learningdisabilityengland.org.uk/activities-ideas/) including an [easy read guide to using WhatsApp](https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism/care-staff)

Find the system which works best for each person you support.

Even as restrictions ease, remember that the people you support 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:

- **Coronavirus anxiety tips** (NHS)
- **Coronavirus: Information from other organisations** (Mencap)
Staying well

Infection control and good personal hygiene

One of the most important things that care providers can do during the pandemic is to ensure that their staff and the people they support are maintaining good personal hygiene, and managing infection control as well as possible. The COVID-19 virus calls for much greater standards of hygiene, both individually, and in the home where the person lives. This can be challenging, because many of the care settings in which autistic people and people with learning disabilities live are designed to be as homely as possible, with an emphasis on comfort and domesticity, not infection control. Good role modelling by staff will therefore be essential, not least because some people may find the changed routines hard to handle. It is important that staff follow government guidance on cleanliness and hand hygiene, particularly when entering or moving between premises.

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:

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

Supporting people with personal hygiene and cleanliness around the house

Although restrictions have eased, the infection rate remains high and people with a learning disability may have health conditions that make them more vulnerable to becoming seriously ill with COVID-19. It would therefore be sensible to continue to take some of the precautions that were advised at the start of the pandemic, and to adhere to them closely should anyone you support become unwell.

- The person that you support is likely to already have a care plan that maximises self-care – so everything the person can do for themselves safely and effectively they should do.
- Some people may simply need prompting, allowing you to keep a safer distance. It is important to explain to the person why you are doing this.
- There may be tasks that you have usually done hands-on with a person, such as tooth-brushing, where prompting may now be possible instead.
• If it is not possible to support someone with hands-on personal care, or assistance with eating, from a distance, then staff should follow Public Health England guidance around providing care and using PPE. Your employer will provide advice and equipment.

• Help the person to understand why you are wearing PPE – some people may be anxious of people wearing PPE, who may be hard to recognise as a result. If you have to wear a mask, consider attaching a laminated photo of yourself to your clothing if that would help the people in your service.

• 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 this may be difficult if the person is distressed - and any skin care issues arising from it addressed.

• Wash all plates and cutlery in hot soapy water. Do not share.

• In group living environments such as residential care and supported living, it is important to support one person at a time and to be vigilant about hygiene before moving on to support another person.

• Cleaning of the home should be done regularly and thoroughly, especially in shared areas. Depending on the setting, this may be the role people you support, or a paid staff member. If the person with learning disabilities is doing the cleaning, it will be important to support them to make sure it is done thoroughly and possibly to a higher (infection control) standard than normal.

• It is everyone’s right to have their own belongings (bedding, towels, clothes, toiletries). Laundry should be done separately with or for individuals and there should be no sharing of any personal items.

**Personal protective equipment (PPE)**

Your employer must carry out a full risk assessment and provide you with all the specialist training and the personal protective equipment (PPE) (gowns/aprons, masks, gloves, etc) that you may require.

Some care staff may be at increased risk of serious illness from COVID-19. Guidance has been issued to support employers to assess and reduce these risks.

Public Health England provide full guidance on the use of PPE and working safely during the COVID-19 outbreak for homecare workers and for workers in care homes.

Staff should also be trained in donning and doffing (putting on and taking off) PPE. Public Health England have produced a video guide to using PPE in care homes which may be helpful.

If you experience problems in accessing PPE, then ask your employer to contact the dedicated helpline for PPE:

Tel: 0800 915 9964 / 0191 283 6543

Email: supplydisruptionservice@nhsbsa.nhs.uk
COVID-19 testing

The NHS Test and Trace service [link 28] aims to provide access to quick testing and to trace contacts of those with a positive result to let them know that they must self-isolate unless they have been fully vaccinated. The NHS COVID-19 app [link 29] can help with contact tracing.

PCR testing is available for anyone with coronavirus symptoms, and for asymptomatic health and care staff, and care home residents. Guidance [link 30] is available detailing the testing procedure that should be followed for residents, staff and professionals visiting care homes. All homcare workers [link 31] can also access weekly PCR testing via their employers. Twice-weekly lateral flow testing is available for personal assistants [link 32].

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 available for everyone.

All information on testing [link 33] relevant to adult social care settings, including a summary, has now been brought together.

Further information on coronavirus testing is available for England [link 34], Wales [link 35], Scotland [link 36] and Northern Ireland [link 37].

### Further reading

#### Healthcare settings

#### Guidance on PPE

#### Residential care
- [Infection prevention and control](https://www.gov.uk/government/publications/infection-prevention-and-control) (Skills for Care)
- [NICE / SCIE guidance for residential care](https://www.gov.uk/government/publications/nice-scie-guidance-for-residential-care)
- [Testing for care homes](https://www.gov.uk/government/publications/testing-for-care-homes)

#### Guidance on home care provision
When to self-isolate

If nobody in a care setting (any staff, or any of the people being supported) is ill or thought to have symptoms, then support can continue in the ordinary way. There should be an additional emphasis on good hand hygiene, trying to avoid touching one’s face, and keeping frequently touched surfaces clean.

**If a care worker develops symptoms (a new continuous cough or fever or loss/change in your sense of smell or taste),** they should isolate and take a test. If it is positive, they must isolate for 10 days, even if they have been fully vaccinated.

Any care worker who has not been fully vaccinated and who either has a symptomatic member of their household or has been in close contact with someone else who has tested positive should also isolate for 10 days and be tested if they develop symptoms.

Anyone who has been fully vaccinated at least 14 days previously does not have to self-isolate if they have been in close contact with someone who has tested positive. Instead, they will be advised to take a PCR test and additional precautions. Health and care staff can usually continue to work if they have a negative PCR test and negative daily lateral flow tests for 10 days.

**Detailed guidance** [link 45](https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism/care-staff) has been issued for staff and managers in health and social care settings.

**If the cared-for person has symptoms,** then care can be provided by the usual carer taking additional precautions and wearing the appropriate personal protective equipment (PPE). Public Health England have provided [advice on the use of PPE for health and social care workers](https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism/care-staff).

Contingency planning

Many people receiving social care support will have plans that consider contingencies for moments of significant change, crisis and ill health. These will also include situations where key individuals and staff teams are unable to continue in their caring role. Usually this will rely on other staff or supports such as family members, or an agency who can provide cover.

If you are worried that you or your organisation do not have a plan in place, or that the impact of the pandemic has made your contingency plans and business continuity harder to action, then you can make a start by doing some important things:

- Talk to the person you support – the more they understand what is happening, the more they will take action to keep themselves safe.
- Think about what will need to be in place if key or other important people to the individual person providing support becomes ill.
- Write down any key contacts (family, neighbours, friends or professionals) who can be called upon for assistance.
- Make sure that information about the support the person needs is available, particularly if they would not be able to communicate this for themselves – for
Where your organisation is having difficulties in running your service, you or your managers must link with the relevant local authority for advice, and to work towards solutions.

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 advice and guidance

It may be that the person you support 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 circumstance with the person you support
- use positive reinforcement wherever possible to encourage the person you support to follow the advice and guidance
- carry out a risk assessment
- 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.

Severe learning disability and behaviour that challenges

If the person that you support 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.

Care providers must do all that they can to support people who may, as a result of changes caused by the pandemic, display more behaviour which challenges the service. Avoiding placement breakdowns wherever possible is important.

Healthcare

Identifying health concerns

You and your staff will know those you support very well. It is important that you use your knowledge of the individual, how they normally are when well, and how they spend their time.
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. Your knowledge of the people you support will help you react quickly if needed and share with health and social care professionals what the person is like when well, and the nature of the change you are concerned about.

It is important to monitor the person you support 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 variant causing most infections currently (known as the Delta variant) has some different symptoms – headache, sore throat, runny nose and fever are most commonly reported. If you think that someone you support may have significant coronavirus symptoms, then follow the procedure to arrange a test or contact NHS 111, online in the first instance, or by phone, for clinical advice.

It is also important to monitor their 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.

Autistic people and people with a learning disability have equal rights to access healthcare, but we know that they 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.

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 must not have a DNACPR put in place without consultation or solely on the basis of having autism, a learning disability, or significant social care support.

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 are at an increased risk of severe illness from coronavirus, but are not in the most high-risk, shielding group:

- 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 a free 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 you support 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](https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism/care-staff) is up to date. If they do not already have a hospital passport there is an emergency COVID-19 passport, and a presentation about [how to fill it in](https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism/care-staff). Learning Disability England has produced an [easy read guide to help support people who may need to go into hospital](https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism/care-staff).

If the person that you support needs to go into hospital because of coronavirus, Mencap have produced some [easy read guides to going into hospital](https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism/care-staff), which may help explain what will happen.

Government advice has been amended to clarify that people with additional support needs, such as people with learning disabilities and autistic people, can have a visitor – family member or care worker – in hospital if they need them. Be led by the person you support, and who they most want with them. Seek advice from your employer if you accompany someone to hospital, in terms of PPE and your own health.

Prior to discharge from hospital into care settings, risk assessments and a revised care plan will need to be done. People should be tested for COVID-19 prior to discharge, and the care setting should be informed of the result.

### Further reading


### 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 as anyone else.

It is good practice 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 the person 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 offer a guide, specific to COVID-19, on Understanding treatments and outcomes in hospital and critical care.

**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](https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism/care-staff) for personalised care and support.

## Safeguarding

There are no changes to safeguarding laws or duties. Autistic people and people with learning disabilities have always been vulnerable to exploitation and abuse, so it is particularly important to remain vigilant at this time and follow good safeguarding practice.

Safeguarding duties and responsibilities apply to adults who:

- have care and support needs
- are experiencing, or at risk of abuse or neglect
- are unable to protect themselves because of their care and support needs.

Autistic people and adults with a learning disability have the right to be fully involved in decisions about their own lives. This includes all decisions relating to this pandemic and the restrictions which come with them. Decisions should never be made without an individual's involvement, or consideration of their best interests. The six key principles of safeguarding serve as a helpful reminder of good practice at this time:

- **Empowerment:** people being supported and encouraged to make their own decisions and give informed consent.
- **Prevention:** it is better to take action before harm occurs.
- **Proportionality:** the least intrusive response appropriate to the risk presented.
- **Protection:** support and representation for those in greatest need.
- **Partnership:** local solutions through services working with their communities.
- **Accountability** and transparency in safeguarding practice.

It is recognised that both people receiving support and those providing support may be anxious at this time. Care workers may themselves require more support than usual and this could result in a more pressured environment. If you are a paid care worker and you notice signs that anyone – you, a colleague, a carer, or the person with learning disabilities themselves – is not coping, do not ignore it. Talk to your manager about your concerns and seek support.

People with learning disabilities living in group settings are among the most vulnerable to abuse, and may sometimes be supported by people who are new to the role, or the individual, particularly if care staff need to isolate. People living alone, who may still be
isolated from others, may be a particular target for those that wish to exploit them, such as scammers and fraudsters.

As a frontline worker you are the eyes and ears that may first pick up any signs of abuse. Here is a checklist of things you can do:

- Talk to your residents or clients about the increased risk of abuse at this time.
- During any period of increased isolation report instantly should anyone new appear to be staying at the property.
- Be aware that any changes in behaviour or demeanour could indicate abuse.
- Advise people living alone not to answer the door to strangers – and be aware of fake ID.
- Try not to alarm people but ask them to be wary of offers to help, particularly from strangers. Suggest that they check with family, friends or other paid support that offers of advice and help are legitimate.
- Warn people against responding to any text, email or phone call from an unidentified source. Explain that fraudsters will imitate official bodies such as the Government or the NHS - and they do it very well! Be aware generally of the risks that people can be subject to online, such as online grooming.
- If you have a concern that someone is being abused or neglected, it is important that you raise that concern internally, in line with your organisation's policy and procedure. This is usually with your direct manager or supervisor. Your organisation may also have a safeguarding lead.
- Please remember the principles of Making Safeguarding Personal, and gain the feelings and wishes, and consent of the individual before reporting. If consent is not given and you believe the individual or others may be at risk you must explain this and record in the referral why you are proceeding.

**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 people with a learning disability or autistic people, will experience the death of a family member, housemate, 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. People with a learning disability and autistic people, of course, experience grief, and having a learning disability or autism does not mean that a person cannot understand or deal with bereavement.

Each person will grieve in their own way and it is important to take a person-centred approach to support them through this process. Having open and honest discussions about death is often the best approach. It is generally advisable to avoid euphemisms like 'gone to sleep' or 'gone to a better place', which can cause confusion, especially with someone people 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, but be prepared to explain the reasons for such emotions.

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

### Further reading

- **Bereavement and learning disabilities: A guide for carers** (Cheshire and Wirral Partnerships NHS)
- **Dealing with bereavement** (Mencap)
- **Loss, bereavement and death** (British Institute of Learning Disabilities)
- **Grief after bereavement or loss** (NHS)
- **Bereavement Advice Centre**
- **Breaking bad news**
- **Dying to matter** (Dimensions)
- **Your Covid Recovery**

### SCIE COVID-19 guides

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

- **A guide for carers/family supporting an adult with learning disabilities and autistic adults through the COVID-19 crisis**
- **A guide for social workers supporting an adult with learning disabilities and autistic adults through the COVID-19 crisis**

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[link 1](https://www.scie.org.uk/mca/introduction)
[link 3](https://www.learningdisabilityengland.org.uk/what-we-do/keeping-informed-and-in-touch-during-coronavirus/)
[link 4](https://www.autism.org.uk/services/helplines/coronavirus.aspx)
[link 5](https://booksbeyondwords.co.uk/coping-with-coronavirus)
[link 6](https://www.youtube.com/playlist?list=PLVgWWNqce4so8XjfhHncVJcjjMfU8u_)
[link 7](https://www.gov.uk/government/publications/face-coverings-when-to-wear-one-and-how-to-make-your-own)