

Coronavirus (COVID-19) advice for social care

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

Updated: 8 January 2021

This is a guide to help care staff and personal assistants supporting adults with learning disabilities and autistic adults through the COVID-19 crisis. Its aim is to assist high-quality care and support during the pandemic. This guide is aimed at supporting you and enabling you and your colleagues to work as safely and proactively as possible.

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** [link 1](#) – 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 are being limited, and everyone is having to make changes to the way we live together and in communities to combat the virus.

This public health crisis is having an acute impact on those with care and support needs, carers and staff. Those you support, and their families, are also likely to be worried about their health; their routines will perhaps have been significantly interrupted; and people may have difficulty understanding rules about social distancing and infection control. All of these issues may be causing 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, and pressures may be exacerbated by people's usual activities (e.g. day support) being curtailed.

Because of your role, you are judged by the government to be an essential worker. That may mean, for example, that you can use priority shopping times in some supermarkets. You will need to take some form of ID with you. If you are a frontline worker delivering social care you are eligible for **coronavirus testing** [link 2](#).

This document is aimed at supporting you and enabling you and your colleagues to work as safely and proactively as possible.

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 current health crisis has increased confusion, fear and anxiety for everyone, and inevitably it will bring additional challenges. 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.

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 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?
- 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 risk posed by the virus 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](#).
- Negotiate, e.g. if we stay in today, we can do your favourite activity.
- 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 exercise daily. Plan with the person taking a daily walk or run.

Here are some resources which may be helpful:

- **Easy read information about the rules to stay at home** [link 6](#) (Public Health England)
- **Easy read advice on how to stay at home** [link 7](#) (Public Health England)
- **National Autistic Society** [link 8](#)
- **Explaining Coronavirus for People with Learning Disabilities and other videos** [link 9](#) (Surrey and Borders Partnership Trust)

The **Royal College of Occupational Therapists** has useful guidance [link 10](#) on staying well during the lockdown.

Social distancing and going out

As the coronavirus is still in general circulation, we need to continue to stay at home wherever possible to minimise the chances of catching and spreading COVID-19.

As infection have again risen rapidly across the country, a national lockdown has been re-introduced and everyone must stay at home. Detailed **guidance explaining the current restrictions** [link 11](#) is available.



If you go out you should always:

- Stay 2 metres (6ft) away from people who are not from your household.
- Wash your hands as soon as you get home.

On 24 July the law changed to make wearing a face mask compulsory in England on public transport and in a wide range of indoor settings.

However, there are some [exceptions](#) ^{link 12}, including for people who need to lip read, and if wearing a mask might cause someone severe distress. The Government have produced some [cards and badges](#) ^{link 13} which you can carry to explain why you cannot wear a face mask. [Jane Green and SEDS](#) ^{link 14} have also produced some exception cards, too.

In England, single adult households – in other words adults who live alone or with dependent children only – can still form a ‘support bubble’ with one other household. All those in a support bubble will be able to spend time together inside each other’s homes, including overnight, without needing to stay 2 metres apart. A household can only form a support bubble with one other household.

Because members of the same household are allowed out together, more than one person with a learning disability and/or autistic person can go out at the same time in a small group, if they live in the same household.

People in [Wales](#) ^{link 15}, [Scotland](#) ^{link 16} and [Northern Ireland](#) ^{link 17} should follow the guidance specific to their country.

If the person you are supporting would normally exercise outside, but they cannot do so in the same way now, then think about how this can be handled with less risk. Are there any quiet open spaces near you? Could you go out at a quieter time? Do you have a garden or could they exercise indoors? Perhaps following a YouTube exercise video would help. Some organisations have produced suggestions for things to do indoors.

- [Resources to help with structure and keeping busy](#) ^{link 18} (Mencap)
- [Visual supports resource pack for parents and carers](#) ^{link 19} (NHS, Hounslow and Richmond Community Healthcare)
- [Keeping busy at home: Activities for parents and carers](#) ^{link 20} (NHS, Hounslow and Richmond Community Healthcare)

Tasks such as shopping or collecting prescriptions are likely to be more stressful than usual, with long waits and too many other people around. It also increases the risks of becoming infected by COVID-19. It may not be helpful to take the person you support with you, even if that is what you normally do, in the interests of developing skills and independence. See if you can have essential items delivered. Most pharmacies and supermarkets will deliver to those with additional needs. [GOV.UK](#) ^{link 21} has some useful information about this.

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 22}. 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.

Where people with learning disabilities and autistic people were living with their partner prior to the current restrictions being introduced, that can obviously continue (with support where necessary).

If people were not living together but did have regular face to face contact with their partner, this will clearly be a difficult time for them. Depending on their living circumstances, and the circumstances of their partner, they may be able to form a support bubble, and so see each other without the social distancing restrictions. If that does not apply they may need additional support with their emotional life. People can continue contact via telephone and video calls, and where appropriate be given the privacy to use technology to continue to have an intimate relationship with their partner. The current national lockdown in England means people can only mix with their own household, with those in their support bubbles and – whilst remaining 2 metres apart – with one person from another household for exercise.

Friendships and relationships with family members are equally important but are currently restricted in the same way.

Autistic people and people with learning disabilities are making 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 be supported wherever it is what the person wants. Learning Disability England have a range of [resources for staying in touch and socialising online](#) ^{link 23}, including an [easy read guide to using WhatsApp](#) ^{link 24}. Find the system which works best for each person you support.

But despite everyone’s best efforts, the people you support may experience loneliness as a result of the reduction in face-to-face opportunities to socialise, connect with family, neighbours and friends, and take part in physical activity and everyday cultural and faith experiences. They may also experience anxiety about the virus outbreak. Some useful resources to support them are

- [How we can all help](#) ^{link 25} (Autism.org)
- [Looking after your feelings and your body](#) ^{link 26} (Public Health England)
- [Coronavirus anxiety tips](#) ^{link 27} (NHS)
- [Coronavirus: Information from other organisations](#) ^{link 28} (Mencap)
- [Explaining Coronavirus for People with Learning Disabilities and other videos](#) ^{link 29} (Surrey and Borders Partnership Trust)

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

- 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 link 30](#) 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.
- Stay vigilant about things that others may have been touched, such as shopping or deliveries to the house.
- 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 link 32](#) has been issued to support employers to assess and reduce these risks.

For people working in care homes or providing homecare (domiciliary care) you should wear the following PPE when in direct contact with the person you support, or within two metres of someone who is coughing. This applies whether or not the person you are supporting has symptoms.

- ✓ Disposable gloves
- ✓ Disposable plastic apron
- ✓ Fluid-resistant surgical mask (FRSM)

Eye protection coverings will be subject to a risk assessment, depending on the individual case

You should also wear a surgical mask when working in communal areas, or performing a task within two metres of people you support that does not require direct contact. But disposable gloves, aprons, and eye protection are not usually required.

Public Health England provide full guidance on the use of PPE and working safely during the COVID-19 outbreak for [homecare workers link 33](#) and for [workers in care homes link 34](#).

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 link 35](#) 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 link 36](mailto:supplydisruptionservice@nhsbsa.nhs.uk)

COVID-19 testing

As essential workers, social care staff are eligible for coronavirus testing. The route to getting tested differs between the four countries, but for many social care staff will be arranged via their employer, though self-referral may also be possible. Testing is also available for the families of essential workers.

Further information on coronavirus testing is available for [England link 37](#), [Wales link 38](#), [Scotland link 39](#) and [Northern Ireland link 40](#).

Further reading

- | | |
|---------------------------------|---|
| Healthcare settings | <ul style="list-style-type: none"> • COVID-19: infection prevention and control (IPC) link 41 (Public Health England) |
| Guidance on PPE | <ul style="list-style-type: none"> • COVID-19 personal protective equipment link 42 (Public Health England) |
| Residential care | <ul style="list-style-type: none"> • Infection prevention and control link 43 (Skills for Care) • NICE / SCIE guidance for residential care link 44 • Testing for care homes link 45 |
| Guidance on home care provision | <ul style="list-style-type: none"> • COVID-19: guidance on home care provision link 46 (Public Health England) |



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 has symptoms (a new continuous cough or fever or loss/change in your sense of smell or taste), they should go home and self-isolate. As essential workers, social care staff are eligible for [COVID-19 testing](#) [link 47](#).

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](#) [link 48](#).

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 example, any information about specific needs, medication or routines.
- ✓ Make a note of where you usually get any specialist supplies (e.g. incontinence supplies).
- ✓ Call the named social worker, social work team or local authority adult social care general contact and ask them to advise, if you can't think of people who could help.
- ✓ Know who the on-call manager is, and how to contact them.

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 [link 49](#) 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 sticking to the guidelines

It may be that the person you support is reluctant to stick to, or does not understand, the rules around social distancing, self-isolation, or the need to wash hands once they are back from a trip out. This can be complex because it causes risks of infection for themselves and for other people. It will not be possible for every person to address this completely, but it may help to:

-  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 stick to the rules
-  carry out a risk assessment
-  mitigate any risks, such as going out at quiet times if the person cannot maintain social distancing, or 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](#) [link 50](#) 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](#) [link 51](#) at this time, and some [FAQs on coronavirus and the law](#) [link 52](#).

Care providers must do all that they can to support people who may at the moment be displaying more behaviour which challenges the service. Avoiding placement breakdowns wherever possible is important, because of the obvious difficulties in planning for and identifying suitable alternative arrangements. If your service is being especially stretched by the increased needs of anyone you support, liaise as early as possible with the person's family and support networks for advice. Speak as well to your local social work team, or Community Team for Learning Disabilities. Have discussions with your commissioners about any possible additional support they may be able to offer.

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 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. If you think that someone you support may have significant coronavirus symptoms, then contact NHS 111, [online](#) [link 53](#) in the first instance, or by phone, for clinical advice. Also contact 111 if symptoms persist for more than seven days. Be sure to explain if the person has a learning disability, and so may be more at risk. But if an autistic person or a person with learning disabilities has only mild, short-lived, symptoms, then there is no need to contact 111. You should continue to seek medical care or support for conditions not related to coronavirus.

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](#) ^{link 54} 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](#) ^{link 55} – one in easy read, and one in plain English.

Shielding and social distancing

Shielding has been re-introduced as part of the current national lockdown. People who are considered to be clinically extremely vulnerable are advised to continue to follow current [government guidance](#) ^{link 56}.

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](#) ^{link 57}.

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.

People who are considered to be clinically extremely vulnerable can register for support.

If the person you support is additionally vulnerable, you should support them to be stringent in following the [social distancing guidance](#) ^{link 58}.

People in the shielding group can register for support by calling the Government's helpline on **0800 028 8327** or visiting [Get coronavirus support as a clinically extremely vulnerable person](#) ^{link 59}.

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](#) ^{link 60} 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](#) ^{link 61}. Learning Disability England has produced an [easy read guide to help support people who may need to go into hospital](#) ^{link 62}, and they have [further advice and resources](#) ^{link 63}.

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](#) ^{link 64}, 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

- [Alert cards for autistic adults and adults with health needs](#) ^{link 65} (Jane Green, InfiniteAutism)
- [Guidance on social distancing for everyone in the UK](#) ^{link 66} (Public Health England)
- [Someone to speak up for you \(advocate\)](#) ^{link 67} (NHS)
- [Health guides](#) ^{link 68} (Mencap)
- [Looking after your feelings and your body easy read](#) ^{link 69} (Public Health England)
- [Guidance on shielding easy read](#) ^{link 70} (Public Health England)
- [Guidance on shielding and protecting extremely vulnerable people from COVID-19](#) ^{link 71} (Public Health England)

Advance decisions to refuse treatment and advance planning

There is a great deal of concern at the moment that some people - especially people with complex health issues - are being pressured into agreeing to DNACPRs, or that GPs and health professionals may be issuing blanket decision across groups of people. This is never acceptable, and care staff have an important role to play in making sure this is not happening to the people they support.

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](#) ^{link 72} 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](#) ^{link 73}.

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



The current crisis has meant that there may be some local [easements to the Care Act 2014](#) [link 74](#) . These changes temporarily amend some of the duties and powers that local authorities have in relation to providing care.

The intention is that these changes will allow local authorities to prioritise meeting the most urgent and acute needs in a time of great pressure on social care services. Any decisions they make will be done in line with the [Ethical Framework for Adult Social Care](#) [link 75](#) . If as a care worker you think the needs of someone you support are not being adequately met by the relevant local authority, this should be raised with the appropriate social work team.

It is important to note that until the local authority has decided to enact the easements locally, and has informed the Department of Health and Social Care, then the usual Care Act requirements remain. You will be informed by the local authority should they choose to enact the easements.

These changes do not affect the Human Rights Act. While the Care Act may be amended locally, the [Mental Capacity Act](#) [link 76](#) – as the legal framework which asserts and supports people’s rights to make their own decisions – has not changed. Duties in the MCA relating to Deprivation of Liberty Safeguards (DoLS) remain in place, as do duties imposed under the Equality Act 2010, although there is [new government guidance](#) [link 77](#) to applying DoLS in the pandemic. Safeguarding duties are not affected by the easements.

▼ Further reading

- [Care Act easements: Guidance for local authorities](#) [link 78](#) (DHSC)
- [Responding to COVID-19: The ethical framework for adult social care](#) [link 79](#) (DHSC)
- [Making it real](#) [link 80](#) (TLAP)

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 now be being supported by people who are new to the role, or the individual. People living alone, now isolated to a greater extent than usual, 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.
- ✓ At this time 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](#) [link 81](#) , 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.

Thousands of new volunteers have been drafted in to the NHS to help. While security checks have been carried out but we must still remain vigilant about any new people providing support. Any concerns should be raised in line with your [safeguarding policy](#) [link 82](#).

Death and bereavement

The current crisis means there is a lot of discussion of death in the media, and there is 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](#) ^{link 83} 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

- [When someone dies from coronavirus: a guide for families and carers](#) ^{link 84} (Books beyond words)
- [Bereavement and learning disabilities: A guide for carers](#) ^{link 85} (Cheshire and Wirral Partnerships NHS)
- [Dealing with bereavement](#) ^{link 86} (Mencap)
- [Loss, bereavement and death](#) ^{link 87} (British Institute of Learning Disabilities)
- [Grief after bereavement or loss](#) ^{link 88} (NHS)
- [Bereavement Advice Centre](#) ^{link 89}
- [Breaking bad news](#) ^{link 90}
- [Dying to matter](#) ^{link 91} (Dimensions)

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](#) ^{link 92}
- [A guide for social workers supporting an adult with learning disabilities and autistic adults through the COVID-19 crisis](#) ^{link 93}

link 1 | <https://www.scie.org.uk/mca/introduction>

link 2 | <https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism/care-staff#testing>

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://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/876699/COVID-19_Keeping_away_from_other_people_20200328.pdf

link 7 | https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/876715/Coronavirus_COVID-19_advice_on_staying_at_home_20200328.pdf

link 8 | <https://www.autism.org.uk/services/helplines/coronavirus.aspx>

link 9 | https://www.youtube.com/playlist?list=PLfVgWWNqce45o8XjfHNCvJCjjMfU8u_

link 10 | <https://www.rcot.co.uk/staying-well-when-social-distancing>

link 11 | <https://www.gov.uk/guidance/national-lockdown-stay-at-home?priority-taxonomy=774cee22-d896-44c1-a611-e3109c8e8eae>

link 12 | <https://www.gov.uk/guidance/coronavirus-covid-19-safer-travel-guidance-for-passengers#exemptions-face-coverings>

link 13 | <https://www.gov.uk/government/publications/face-coverings-when-to-wear-one-and-how-to-make-your-own>

link 14 | <https://www.sussexeds.com/covid-19-1>

link 15 | <https://gov.wales/coronavirus>

link 16 | <https://www.gov.uk/guidance/coronavirus-covid-19-information-for-individuals-and-businesses-in-scotland>

link 17 | <https://www.nidirect.gov.uk/campaigns/coronavirus-covid-19>

link 18 | <https://www.mencap.org.uk/advice-and-support/health/information-about-coronavirus/coronavirus-ways-keep-busy>

link 19 | <https://www.scie.org.uk/files/care-providers/coronavirus/pbs-visual-supports-resource-pack.pdf>

link 20 | <https://www.scie.org.uk/files/care-providers/coronavirus/keeping-busy-at-home-activities.pdf>

link 21 | <https://www.gov.uk/find-coronavirus-support>

link 22 | <https://covidmutualaid.org/>

link 23 | <https://www.learningdisabilityengland.org.uk/what-we-do/keeping-informed-and-in-touch-during-coronavirus/connecting-people-including-webinars/>

link 24 | <http://www.learningdisabilityengland.org.uk/wp-content/uploads/2020/03/whatsapp-an-easy-read-guide-DRAFT-v2.0.pdf>

link 25 | https://www.autism.org.uk/advice-and-guidance/topics/coronavirus?gclid=EAlaIQobChMI2aCRz7n67AIVKoBQBh3iLQI0EAAYASAAEgI8D_D_BwE

link 26 | https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/876996/Easy_read_looking_after_your_feelings_and_body.pdf

link 27 | <https://www.nhs.uk/oneyou/every-mind-matters/coronavirus-covid-19-anxiety-tips/>

link 28 | <https://www.mencap.org.uk/advice-and-support/health/information-about-coronavirus/coronavirus-information-other-organisations>

link 29 | https://www.youtube.com/playlist?list=PLfVgWWNqce45o8XjfHNCvJCjjMfU8u_

link 30 | <https://www.gov.uk/government/publications/wuhan-novel-coronavirus-infection-prevention-and-control/covid-19-personal-protective-equipment-ppe>

link 31 | <http://healthvideos.hci.digital/coronavirus>

link 32 | <https://www.gov.uk/government/publications/coronavirus-covid-19-reducing-risk-in-adult-social-care/covid-19-adult-social-care-risk-reduction-framework>

link 33 | <https://www.gov.uk/government/publications/covid-19-how-to-work-safely-in-domiciliary-care>

link 34 | <https://www.gov.uk/government/publications/covid-19-how-to-work-safely-in-care-homes>

link 35 | <https://www.youtube.com/watch?v=ozY50PPmsvE&feature=youtu.be>

link 36 | <mailto:supplydisruptionservice@nhsbsa.nhs.uk>

link 37 | <https://www.gov.uk/guidance/coronavirus-covid-19-getting-tested>

link 38 | <https://gov.wales/key-critical-workers-testing-policy-coronavirus-covid-19>

link 39 | <https://www.gov.scot/publications/coronavirus-covid-19-testing-for-key-workers-in-scotland/>

link 40 | <https://www.publhealth.hscni.net/covid-19-coronavirus/coronavirus-national-testing-programme-key-workers>

link 41 | <https://www.gov.uk/government/publications/wuhan-novel-coronavirus-infection-prevention-and-control>

link 42 | <https://www.gov.uk/government/publications/wuhan-novel-coronavirus-infection-prevention-and-control/covid-19-personal-protective-equipment-ppe>

link 43 | <https://www.skillsforcare.org.uk/Learning-development/ongoing-learning-and-development/infection-prevention-control/Infection-prevention-and-control.aspx>

link 44 | <https://www.scie.org.uk/publications/ataglance/helping-to-prevent-infection.asp>

link 45 | <https://www.gov.uk/apply-coronavirus-test-care-home>

link 46 | <https://www.gov.uk/government/publications/covid-19-residential-care-supported-living-and-home-care-guidance/covid-19-guidance-on-home-care-provision>



link 47 | <https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism/care-staff#testing>

link 48 | <https://www.gov.uk/government/publications/wuhan-novel-coronavirus-infection-prevention-and-control/covid-19-personal-protective-equipment-ppe>

link 49 | <https://www.togethermatters.org.uk/resources-and-information/>

link 50 | <https://www.challengingbehaviour.org.uk/information/covid19information.html>

link 51 | <https://www.challengingbehaviour.org.uk/learning-disability-assets/3challengingbehavioursupportingyourlovedoneathome.pdf>

link 52 | <https://www.challengingbehaviour.org.uk/learning-disability-assets/covid19faqsfromlegalpanel3.pdf>

link 53 | <https://111.nhs.uk/>

link 54 | <https://www.gov.uk/government/collections/reasonable-adjustments-for-people-with-a-learning-disability>

link 55 | <https://www.england.nhs.uk/coronavirus/publication/getting-nhs-help-when-you-need-it-during-the-coronavirus-outbreak/>

link 56 | <https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19>

link 57 | <https://www.nhs.uk/conditions/vaccinations/who-should-have-flu-vaccine/>

link 58 | <https://www.gov.uk/government/publications/covid-19-guidance-on-social-distancing-and-for-vulnerable-people/guidance-on-social-distancing-for-everyone-in-the-uk-and-protecting-older-people-and-vulnerable-adults>

link 59 | <https://www.gov.uk/coronavirus-extremely-vulnerable>

link 60 | <https://www.mencap.org.uk/advice-and-support/health/health-guides>

link 61 | <https://www.learningdisabilityengland.org.uk/wp-content/uploads/2020/03/LDE-hospital-passport-session.pdf>

link 62 | <http://www.learningdisabilityengland.org.uk/wp-content/uploads/2020/03/Hospital-and-coronavirus-widgit.pdf>

link 63 | <https://www.learningdisabilityengland.org.uk/what-we-do/keeping-informed-and-in-touch-during-coronavirus/resources-that-can-help/>

link 64 | <https://www.mencap.org.uk/advice-and-support/health/information-about-coronavirus/coronavirus-information-about-going>

link 65 | <https://www.basw.co.uk/media/news/2020/apr/alert-cards-autistic-adults-and-adults-health-needs>

link 66 | <https://www.gov.uk/government/publications/covid-19-guidance-on-social-distancing-and-for-vulnerable-people/guidance-on-social-distancing-for-everyone-in-the-uk-and-protecting-older-people-and-vulnerable-adults>

link 67 | <https://www.nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/someone-to-speak-up-for-you-advocate/>

link 68 | <https://www.mencap.org.uk/advice-and-support/health/health-guides>

link 69 | https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/876996/Easy_read_looking_after_your_feelings_and_body.pdf

link 70 | https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/900783/New_guidance_protecting_people_most_likely_to_get_very_poorly_from_coronavirus_Easy_read.pdf

link 71 | <https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19>

link 72 | <https://compassionindying.org.uk/>

link 73 | <https://www.criticalcare.nice.org.uk/patient-information>

link 74 | <https://www.gov.uk/government/publications/coronavirus-covid-19-changes-to-the-care-act-2014/care-act-easements-guidance-for-local-authorities>

link 75 | <https://www.gov.uk/government/publications/covid-19-ethical-framework-for-adult-social-care/responding-to-covid-19-the-ethical-framework-for-adult-social-care>

link 76 | <https://www.scie.org.uk/mca/introduction>

link 77 | <https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism/care-staff>

link 78 | <https://www.gov.uk/government/publications/coronavirus-covid-19-changes-to-the-care-act-2014/care-act-easements-guidance-for-local-authorities>

link 79 | <https://www.gov.uk/government/publications/covid-19-ethical-framework-for-adult-social-care/responding-to-covid-19-the-ethical-framework-for-adult-social-care>

link 80 | <https://www.thinklocalactpersonal.org.uk/makingitreal/about/>

link 81 | <https://www.local.gov.uk/our-support/our-improvement-offer/care-and-health-improvement/making-safeguarding-personal>

link 82 | <https://www.scie.org.uk/care-providers/coronavirus-covid-19/safeguarding-adults>

link 83 | <https://www.scie.org.uk/person-centred-care>

link 84 | <https://booksbeyondwords.co.uk/downloads-shop/when-someone-dies-from-coronavirus>

link 85 | <http://www.cwp.nhs.uk/media/3508/bereavement-and-learning-disabilities-a-guide-for-carers-master.pdf>

link 86 | <https://www.mencap.org.uk/advice-and-support/dealing-bereavement>

link 87 | https://www.thh.nhs.uk/documents/_Patients/PatientLeaflets/general/Bereavement-BILD.pdf

link 88 | <https://www.nhs.uk/conditions/stress-anxiety-depression/coping-with-bereavement/>

link 89 | <https://www.bereavementadvice.org/topics/coping-with-grief-and-bereavement-advice/useful-contacts/>

link 90 | <http://www.breakingbadnews.org/>

link 91 | <https://www.dimensions-uk.org/search-results/?q=dying+to+matter>

link 92 | <https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism/carers-family>

link 93 | <https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism/social-workers>

link 94 | <https://www.scie.org.uk/myscie/register>

link 95 | <https://www.scie.org.uk/myscie/login>

