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Guidance

# Coronavirus (COVID-19): providing unpaid care to adults with learning disabilities and autistic adults

Updated 10 May 2021

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Applies to: England

## Who this guidance is for

This guidance is for those who provide unpaid care, such as friends or family, to adults with learning disabilities and autistic adults.

This guidance aims to help those with caring responsibilities keep people with learning disabilities and autistic people safe, to support them to understand the changes they need to make during the COVID-19 outbreak, and to protect their own wellbeing.

The outbreak and the measures that have been put in place will have an impact on everyone's lives and may result in increased stress and anxiety for both carers and the people they look after, as routines and care provision change. This may be heightened for people with learning disabilities and autistic people and it is important to continue to consider their unique needs and preferences. All care and support should continue to be given in the least restrictive way possible and continue to maximise independence wherever possible.

This guidance builds on the guidance for those who provide unpaid care to friends or family (<https://www.gov.uk/government/publications/coronavirus-covid-19-providing-unpaid-care>) and more detailed guidance published by the Social Care Institute for Excellence (SCIE) (<https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism>) with resources to support those who care for people with learning disabilities and autistic people.

The advice and resources may also be helpful for those supporting people with other needs relating to a cognitive impairment, such as dementia or mental health conditions.

There is additional advice for people who are clinically extremely vulnerable to coronavirus (<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>) and households with a possible or confirmed coronavirus infection (<https://www.gov.uk/government/publications/covid-19-stay-at-home-guidance/stay-at-home-guidance-for-households-with-possible-coronavirus-covid-19-infection>).

## Protecting yourself and the person you care for

### Maintaining good hygiene practices

Cleaning your hands frequently throughout the day by washing with soap and water for at least 20 seconds or using hand sanitiser is one of the most effective ways of reducing the risk of infection for you and other people. This includes when you arrive at the home of the person you care for, if you do not live with them, or have been out.

The stay at home guidance (<https://www.gov.uk/government/publications/covid-19-stay-at-home-guidance>) provides information on washing your hands, cleaning and disposing of waste, and cleaning laundry, as well as other information for those living with a vulnerable person. You should also refer to the guidance on hygiene on the NHS website (<https://www.nhs.uk/conditions/coronavirus-covid-19/>).

### Planning in case of an emergency

As set out in the guidance for those who provide unpaid care to friends or family (<https://www.gov.uk/government/publications/coronavirus-covid-19-providing-unpaid-care>), we advise all carers to create an emergency plan with the person they care for, to use in circumstances where other people may need to help deliver care. Depending on the circumstances, this could be help from family or friends, or a care provider.

In order to create an emergency plan that fits the needs of the person you care for, you will need to set out:

- the name and address and any other contact details of the person you look after
- who you and the person you look after would like to be contacted in an emergency
- details of any medication the person you look after is taking
- details of any ongoing treatment they need
- details of any medical appointments they need to keep
- details of their preferences and usual routine

You should also make sure that it is in a format that can readily be shared with other people who will need to discuss the plan with the person you care for.

For more support on contingency planning, see Carers UK guidance (<https://www.carersuk.org/help-and-advice/practical-support/planning-for-emergencies>) on practical support and planning in an emergency, including information about local carer organisations. You can also find information out about local services on the Carers Trust website (<https://carers.org/our-work-locally>).

## **Collecting prescriptions if you are self-isolating**

If you normally collect prescriptions for the person you care for, you will not be able to do this if you are self-isolating. Most pharmacies provide a home delivery service. Telephone them to see if this is available or if there is another scheme running locally to help you access prescriptions.

Pharmacy delivery services will be under pressure at the moment, so it is important that you order your repeat prescriptions in good time, to avoid delays in dispensing. Information on repeat prescriptions and delivery services may also be available via your GP practice website.

## **If the person you care for is concerned about their usual paid carer coming in and out of their home**

The government has issued guidance to home care providers (<https://www.gov.uk/government/publications/covid-19-residential-care-supported-living-and-home-care-guidance/covid-19-guidance-on-home-care-provision>) to ensure that appropriate levels of hygiene are achieved to reduce the risk of infection. Speak to the care provider about the processes they are following to maintain good hygiene.

If the person you care for receives regular health or social care from an organisation, either through your local authority (<https://www.gov.uk/find-local-council>) or paid for by themselves, inform their care provider that they are reducing social contacts and agree on a plan for continuing their care, identifying essential care tasks that should continue.

## **If the person you care for is in a care home**

If you have no symptoms, you should keep in contact with the care home to understand any local arrangement to keep in touch with residents. You should follow the latest advice as set out in the guidance on the national lockdown (<https://www.gov.uk/guidance/national-lockdown-stay-at-home>).

## **Caring for someone who is clinically 'extremely vulnerable' (shielding)**

Some people with learning disabilities or autistic people may have a specific health condition and may be clinically defined as 'extremely vulnerable'. The guidance on shielding and protecting the clinically extremely vulnerable (<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>) and the guidance for those who provide unpaid care to friends or family (<https://www.gov.uk/government/publications/coronavirus-covid-19-providing-unpaid-care>) provides detailed advice on how to care for someone who falls into this category.

The NHS in England is directly contacting people with these conditions to provide further advice. If you think the person you care for falls into the clinically 'extremely vulnerable' group and they have not received a letter or been contacted by their GP, you should discuss your concerns with their GP.

### **If you are clinically 'extremely vulnerable'**

If you are in the group clinically defined as 'extremely vulnerable', you should follow the measures set out in the guidance for clinically extremely vulnerable groups (<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>). The advice should still be followed even if you do not have symptoms.

### **If you have symptoms of COVID-19**

If you or someone in your household has symptoms, you should follow the stay at home guidance (<https://www.gov.uk/government/publications/covid-19-stay-at-home-guidance>). The guidance provides detailed advice on when and how to self-isolate and information on cleaning and hygiene.

However, we appreciate that the advice above may not be easy to achieve where you provide close contact care for a spouse or relative such as washing and bathing. Where possible and needed, ask friends and family who can support you in providing care, or find out about local carer organisations at Carers UK (<https://www.carersuk.org/help-and-advice/get-support/local-support>) or through your local authority (<https://www.gov.uk/find-local-council>).

### **If the person you care for has symptoms of COVID-19**

If the person being cared for has symptoms or is part of a household that is isolating, you must follow the advice set out in the stay at home guidance (<https://www.gov.uk/government/publications/covid-19-stay-at-home-guidance>) and the guidance for those who provide unpaid care to friends or family (<https://www.gov.uk/government/publications/coronavirus-covid-19-providing-unpaid-care>).

If you do not live in the same home as the person you care for, you should provide information on who the person should call if they feel unwell, how to use the NHS 111 online coronavirus service (<https://111.nhs.uk/covid-19>) and leave the number for NHS 111 prominently displayed.

## **Supporting the person through change**

## Communication

Changes in routines and care can be particularly stressful for people with learning disabilities and autistic people, and it is important that accessible information is provided to support them to understand the outbreak and the measures introduced. You may also need to consider how to manage behaviour that challenges, particularly if usual techniques are not appropriate or possible during the outbreak.

There are some steps you can take and guidance you can follow to support the person you care for through change:

- Try to explain in simple and familiar terms why things are changing, emphasising what will remain normal and how long change will likely last for.
- Consider where you can support them to continue doing what they enjoy and that can support their wellbeing. The guidance on mental health and wellbeing (<https://www.gov.uk/government/publications/covid-19-guidance-for-the-public-on-mental-health-and-wellbeing>) offers examples of activities that can be done at home.
- The Challenging Behaviour Foundation (<https://www.challengingbehaviour.org.uk/information/covid19information.html>) has helpful resources, including a visual summary of what to do if the behaviour of the person you support changes and begins to challenge (<https://www.challengingbehaviour.org.uk/learning-disability-assets/supportingchildrenandadultswithsevrelarningdisabilitesathomeduringthecoronaviruspandemic.pdf>).

It is important to use resources which are accessible and can best explain the outbreak and latest guidance to the person, such as:

- easy read version of the ethical framework for adult social care (<https://www.gov.uk/government/publications/covid-19-ethical-framework-for-adult-social-care>)
- resources by MENCAP (<https://www.mencap.org.uk/advice-and-support/coronavirus-covid-19/coronavirus-guidance-help-you-stay-safe-and-well>) and Learning Disability England (<https://www.learningdisabilityengland.org.uk/what-we-do/keeping-informed-and-in-touch-during-coronavirus/>)
- World Health Organization guide to effective hand-washing ([https://www.who.int/gpsc/clean\\_hands\\_protection/en/](https://www.who.int/gpsc/clean_hands_protection/en/))
- music video made by people with learning disabilities to support effective handwashing (<https://youtu.be/4eY59qr2FTo>)

## Social distancing

The government has published the COVID-19 Response - Spring 2021

(<https://www.gov.uk/government/publications/covid-19-response-spring-2021>) setting out the roadmap out of the current lockdown for England. This explains how restrictions will be eased over time.

Some of the rules on what you can and cannot do changed on 12 April. However, many restrictions remain in place. Find out what you can and cannot do (<https://www.gov.uk/guidance/covid-19-coronavirus-restrictions-what-you-can-and-cannot-do>).

It is important that the person you care for understands why it is important to maintain a social distance, and what may happen if they do not.

However, if the person in your care has a specific health condition which requires them to leave their home to maintain good health – including if that involves reasonable specific travel beyond your local area – then they can do so. This could, for example, include where people with learning disabilities or autistic people require specific exercise in an open space 2 or 3 times each day – ideally in line with a care plan agreed with a medical professional.

Wherever possible, you should support the person to continue their usual activities outside, in line with the restrictions that apply at the time. If it is not possible to continue their usual activities outside, alternative arrangements should be considered. These may include accessing online services such as food delivery or online prescription orders.

You may be able to access help from COVID-19 Mutual Aid UK (<https://covidmutualaid.org/>) which provides voluntary support to those who are in need. You may want to approach your local authority, who are strategically supporting these groups, so you can access safe, appropriate support.

## Coping with bereavement

It is possible that the person you care for may experience the death of someone they know during this period or may experience anxiety at deaths reported in the media. In this instance, it is important to have open and honest discussions about death and coping with the person you care for.

The links below provide accessible resources to support communicating death to people with learning disabilities and autistic people:

- NHS advice on coping with bereavement (<https://www.nhs.uk/conditions/stress-anxiety-depression/coping-with-bereavement/>)
- Beyond Words guide for when someone dies from coronavirus (<https://booksbeyondwords.co.uk/downloads-shop/when-someone-dies-from-coronavirus>)
- CWP NHS Trust bereavement guide for carers (<http://www.cwp.nhs.uk/media/3508/bereavement-and-learning-disabilities-a-guide-for-carers-master.pdf>)
- MENCAP guide to dealing with bereavement (<https://www.mencap.org.uk/advice-and-support/dealing-bereavement>)

## Maintaining your own health and wellbeing

It is important that you look after your own health and wellbeing as well as supporting others you care for, especially given the potential for additional stresses at the current time and the potential for reduced access to support such as respite care.

There is information in the stay at home guidance (<https://www.gov.uk/government/publications/covid-19-stay-at-home-guidance>) about looking after your wellbeing, as well as more detailed guidance on self-care and sources of support for mental health and wellbeing during the outbreak (<https://www.gov.uk/government/publications/covid-19-guidance-for-the-public-on-mental-health-and-wellbeing/guidance-for-the-public-on-the-mental-health-and-wellbeing-aspects-of-coronavirus-covid-19>).

Tips include taking care of your mind as well as your body and getting support if you need it. Daily physical activity is important for many aspects of health and wellbeing, including managing stress, encouraging positive feelings, and promoting good sleep habits. The One You website has suggestions for exercises you can do at home (<https://www.nhs.uk/oneyou/for-your-body/move-more/home-workout-videos/>).

Draw on support you might have through your friends, family and other networks during this time. Try to stay in touch with those around you over the phone, by post, or online. Let people know how you would like to stay in touch and build that into your routine.

Remember it is OK to share your concerns with others you trust and in doing so you may be able to provide support to them too. There are sources of support and information that can help, such as NHS recommended helplines (<https://www.nhs.uk/conditions/stress-anxiety-depression/mental-health-helplines/>), and the Every Mind Matters (<https://www.nhs.uk/oneyou/every-mind-matters/>) website.

It may also be helpful to contact your local carers support organisation who can help with contingency planning. You can find out about local carer organisations at Carers UK (<https://www.carersuk.org/help-and-advice/get-support/local-support>). There is also an online forum on Carers UK (<https://www.carersuk.org/forum>).

## **Accessing alternative care quickly if you are unable to provide care**

Having to organise alternative care can be difficult and concerning. Where possible, you should contact friends and family who may be able to give immediate help in providing care. You should follow the latest guidelines to protect those coming into the home of the person who needs care.

If you cannot organise alternative care you can contact your local authority (<https://www.gov.uk/find-local-council>) or health care provider (<https://www.nhs.uk/service-search>).

If you do not know how to do this, you can contact NHS 111.

## **If you need time off work to care for a relative who has symptoms or is self-isolating**

You should talk to your employer about your caring needs and what arrangements can be put in place. Information regarding statutory sick pay entitlements can be found in the guidance for employees (<https://www.gov.uk/government/publications/guidance-to-employers-and-businesses-about-covid-19/covid-19-guidance-for-employees>).

Some people may be entitled to benefits as a carer, such as Carer's Allowance (<https://www.gov.uk/carers-allowance>).

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