

Learning disability and autism, dementia and mental health engagement and communication advice

Advice for people with a learning disability, autistic people, people with mental health conditions and dementia about engaging with services.

We are living through a difficult and unprecedented time that is challenging for many people across the country. For people with a learning disability, autistic people, people with a mental health condition or dementia there may be extra challenges, and people may experience a whole range of difficult emotions or be experiencing emotional distress. Some may be struggling with feeling lonely and isolated, some perhaps are feeling anxious or worried, or are struggling to get basic needs like food and medicine.

We want you to know that NHS services, including mental health and learning disability services, are still very much open and here to support you. This document offers advice on how to get in touch with services and to get access to the support and help you may need.

Accessing support from services

- Don't let a concern about coronavirus stop you from seeking medical care or attention when you need it – whether your symptoms are linked to coronavirus or not. NHS services are open to support you, so please do contact them.
- If you are worried about coronavirus, use the support lines that are available.
- Use the accessible information available on coronavirus on official sites such as gov.uk or nhs.net, NHS.uk or any other local NHS or government site.
- In these difficult times, be aware that services may be affected and may need to work in different ways. They should explain if any changes are made to your care and support. Face-to-face appointments may not be possible, but services should talk to you about this and offer an alternative.

- If you are in hospital you should be supported to maintain contact with your family using the telephone or the internet. Staff should support you to do this. Visits are allowed too in line with the latest visitor guidance here <https://bit.ly/3hUAo55>. There is also specific guidance about visiting people who are in a mental health, learning disability or autism inpatient setting sent in a letter which you can view here <https://bit.ly/3bljfQL> from Claire Murdoch, National Mental Health Director and Ray James, National Director for Learning Disability and Autism that sets out expectations for visiting in these settings.
- Make sure people understand the impact on you (or if it is appropriate, your family) if your care and support package has changed. You can contact the central advice and duty teams in your area to discuss this. You can find this number on your local authority website. Your social worker should be giving you information about this. If you need to find out details about your local authority, see find your local council here - <https://www.gov.uk/find-local-council>.
- You can challenge any rules or decisions made for whole groups of people, rather than on an individual basis, because they affect your care and support package (this is sometimes called a blanket restriction or decision). Changes should only be made on an individual basis after your needs, and the risk of changing your care and support, has been considered.

Some things you can do to help.

- Don't be afraid to ask for advice or support – talk to friends, family, advocates and others who support you; stay connected with people. You can do this using the telephone, Skype, Facetime, Microsoft Teams, WhatsApp, and there are lots of other apps that will support you with this. You can find resources for: Easy Read WhatsApp Guidance here - <https://bit.ly/3nsGuLj> and Easy Read Microsoft Teams Guidance here - <https://bit.ly/2XmaVYV>
- If you don't have access to, or find it difficult to use these things, talk to someone you trust about what might be the best way for you to stay in touch, and let them know you need help if you do.
- Let people know if you don't have the right equipment to communicate with them via the internet or social media; you might be able to get some help with this. Talk to your social worker, keyworker, care co-ordinator or other professional involved with your care and treatment.
- Be prepared – try to make sure your health passport, health action plan and any other health documents you have are up to date. You can ask your supporter, friends, community nurse, social worker or carer to help you do this.

Advice for family and carers about engaging with services

As well as looking after your own wellbeing and planning ahead (see government guidance on health and wellbeing here <https://bit.ly/3q1LYys> and Carers UK resources on wellbeing here <https://bit.ly/2JYLObG>), it is important that family and carers:

- Are not afraid to ask for help if (you) or your family member is at risk of crisis (e.g. through your social worker, health commissioner or local authority helpline).
- Know the current status of important appointments (in education, health or social care), what is happening about them and how or when they will happen (e.g. if they are being reorganised or moved online).
- Ensure fear of COVID-19 doesn't prevent them from seeking urgent medical attention for other non COVID-19 illnesses during this period (e.g. toothache) or from keeping up to date with existing health needs (e.g. putting in prescriptions for medications). Health services are putting in place lots of precautions to prevent the spread of COVID-19, with many reconfigured to separate patients with symptoms of COVID-19 from those without.
- Are not afraid to raise concerns and challenge:
 - any discrimination in care and treatment that does not respect your family member's rights and their need for reasonable adjustments.
 - diagnostic overshadowing: this can be when a health professional assumes that the behaviour of a person with a learning disability, mental health condition, dementia or an autistic person is part of their disability or is a symptom of mental illness, without exploring other factors that may be causing the behaviour – e.g. being physically unwell. Be confident about challenging diagnostic overshadowing by clearly sharing what is normal for the individual, what has changed and why you are concerned.
 - decisions made about care and treatment without appropriate risk assessments
 - where you see the do not attempt cardiopulmonary resuscitation (DNACPR) recommendation being made because of a disability diagnosis, age or other protected characteristics, rather than on an individual, person-centred approach. A DNACPR decision means that if the person's heart stops beating, they have a cardiac arrest and will be allowed a natural death rather than CPR being attempted.

- Keep in touch when unable to physically visit your family member (e.g. in a care home or a mental health inpatient setting where visiting has been restricted to prevent the spread of coronavirus), and work creatively with commissioners and providers to ensure contact continues remotely and the needs and rights of your family member are respected. Contact providers about visiting arrangements as face-to-face visiting is now supported in line with the latest visitor guidance which you can view here <https://bit.ly/39aakiF>. If you have difficulty accessing or knowing how to use technology, then let professionals know if you either don't have the equipment or knowledge and ask them how they can help with this.
- Recognise the challenging conditions many clinicians and professionals are now working in – and understand if things are not always done as quickly as you might like, but don't leave things unaddressed if they are important for you or your family member.
- Seek information and advice from trusted sources, both locally and nationally (e.g. www.nhs.uk, Contact, Challenging Behaviour Foundation, National Autistic Society, Childline, MIND, Rethink, Carers UK, Dementia UK), as well as booklets such as Supporting carers and care staff to understand and respond to changes in behaviour in people with dementia during the COVID-19 pandemic, to help you and your family member stay safe and happy: <https://www.dementiavoices.org.uk/supporting-carers-and-care-staff-to-understand-and-respond-to-changes-in-behaviour-in-people-with-dementia-during-covid-19>

3. Advice for parents and carers of children and young people (including foster carers)

- If you are the parent or carer of a child or young person, the Council for Disabled Children <https://bit.ly/3bl9P88> has a range of support and advice available in relation to COVID-19.
- The Department for Education has information and guidance on its website about what is happening for children and young people, access to schools and how children they class as vulnerable continue to be supported. See Coronavirus: guidance for schools and other educational settings - <https://bit.ly/3bjfKun>
- The Department for Education, NHS England and NHS Improvement, and the Department for Health and Social Care will be preparing some frequently asked questions answers in relation to children and young people. If you have any questions you can send them to CDCquestions@ncb.org.uk or through your local parent carer forum here - <https://bit.ly/3nv14KR>
- If you are a young carer looking after a family member, you can find more information by visiting support for young carers - <https://bit.ly/38uW7Oh>. You can also find helpful information from the Department of Health and Social Care - <https://bit.ly/3nrt7uE>