

# **Guidance and advice on coronavirus (COVID-19) What does this mean for me and my family?**

Learning Disability and Autism focus



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## About this document

This document brings together different advice from GOV.UK and the NHS. A full list of documents used in this advice can be found in the Appendix.

This document focuses on supporting children and young people with autism and a learning disability. A further CDC document summarises and simplifies general guidance for supporting children and young people's mental health and wellbeing at this time.

## Top tips for emotionally supporting children and young people with a learning disability, autism or both

### Children and young people with a learning disability

Children and young people with a learning disability may feel:

- A loss of control
- Anxious about big changes, such as going to new places or the possibilities of having to stay at home for a long period.

Children with a learning disability, particularly those with a severe learning disability, may not be able to understand why things have changed and why their routines and contact with other people are different. This can be very upsetting and can also lead to challenging behaviour.

The Challenging Behaviour Foundation has many useful resources, such as [Supporting Your Loved One at Home](#). See the [Resource section](#) for further information.

Children may need:

- Extra words of reassurance;
- More explanations or adapted explanations about the event;
- More comfort and other positive physical contact from loved ones;
- New routines and timetables developed to help them cope;
- Specific behaviour support.

A good way to help them is by supporting them to make decisions and express emotions, for example using:

- Written words;
- Pictures;
- Symbol systems.

Support them by:

- Letting them know they are not alone;
- Organising fun activities that you know they enjoy and can achieve;
- Taking their feelings seriously and not judging their emotions;
- Explaining any upcoming changes to routine before they happen and helping them to plan and come up with solutions;
  - For example finding a hobby or doing exercises to relax and cope with anxiety.



Useful resources:

- Talking about feelings, see [Skills for Care advice](#);
- Books beyond words (currently free to download), see <https://booksbeyondwords.co.uk/downloads-shop/beating-the-virus>
- Accessible information about coronavirus, including Easy Read: [Mencap website](#);
- Information about supporting children with a learning disability or autism whose behaviours challenge: [Challenging Behaviour Foundation website](#).

## Children and young people with autism

Autistic children and young people might struggle with:

- Identifying physical symptoms of coronavirus;

- Talking about their emotions;
- Changes to routines.

Keep an eye out for changes in behaviour that may help you to understand their emotions as well as any symptoms.

When talking to them:

- Be clear;
- Avoid definitive statements (for example, 'it will be fine in time for your birthday') as this may upset them further if things change more.



You know your child or young best person, so continue:

- Using coping strategies that work for them;
- Supporting their physical wellbeing in a way that works for them;
- Getting support from local autism groups online or on the phone.

Useful resources:

- [National Autistic Society guidance on managing anxiety](#)
- [Autism helpline](#) (currently running via webform)
- [Autistica's advice on coping with Coronavirus](#)

## Top tips for when accessing medical and clinical support

- Children and young people with autism and or a learning disability can:
  - Experience physical ill-health differently to others;
  - Struggle to understand or talk about their symptoms;

- Be unaware of the specific pain or health issue causing discomfort which may result in behaviour changes.

At times, a physical health condition can be confused with or misunderstood as being related to a child or young person's autism and/or learning disability.

To help with this:

- Use an [All About Me profile](#), [Health Passport](#) or [Hospital Passport](#) to share a child or young person's needs with professionals;
- Include any communication support needs that child or young person's has;
  - This includes body language and vocalisations (sounds they make with their voice) as well as things like PECS and Makaton.
    - How do they look and sound when they are comfortable and happy?
    - How do they look and sound when they are uncomfortable or distressed?
  - A [Communication Passport](#) might be useful.
- Share information about the child or young person and what is normal for them with professionals;
- Be aware of your child or young person's [right to reasonable adjustments](#);
- If your child is over 16, be aware of [the Mental Capacity Act](#);
- Support your child to understand any new or frightening aspects of being in a medical environment, such as masks or protective clothing;
- Request the support of a Learning Disability Nurse



## Accessing medical care and support during coronavirus for other symptoms

We know many families will be anxious about going out during coronavirus or may not want to place any further pressure on the NHS, but please

remember that it is still very important to seek medical advice and support if your child is unwell with any other types of symptoms or illness that is not potentially related to coronavirus.

## Children and young people accessing mental health services

Children and young people with who have a mental health condition might find the current uncertainty particularly difficult. If they are more stressed, their behaviour and mental health needs might change.

If you are worried about getting support if they need to stay at home:

- Speaking to your child or young person's mental health team about any worries and existing support. Update any safety and care plans as agreed.
  - Ask if there are other ways that they can get their support;
    - For example, appointments by phone, text or online.

If you usually have support in your own home:

- Check who you would need to contact in your local authority to let them know that you're staying at home. Make sure that they know if your child or young person still needs support.

If your child or young person has been admitted to an inpatient mental health unit:

- Talk to staff about their policies on access to mobile phones or other forms of digital access to enable you to virtually stay in touch;
- Think about how you can stay in contact, particularly if you have to stay at home;
- Ask the unit if you could participate in a 'virtual ward round' so you can keep in touch with your child and/or young person's mental health team;
- Talk to your child or young person about what might happen if you have to stay at home so they are fully informed;



- Particularly if this has an impact on visits or leave.
- If your child or young person becomes affected by coronavirus:
  - Talk to the unit about what plans are in place should this happen and how best to communicate these to your child or young person.

*New guidance is due to be published soon, which will set out what to expect if a person with a learning disability or an autistic person who is an inpatient in a specialist mental health or learning disability hospital becomes ill with coronavirus. We will update this resource when that guidance is available.*

## Questions you might have

What is the government doing about children in residential schools or with EHC plans, and CETRs (Care, Education and Treatment Review)?

NHS England and Improvement is working with colleagues in the Department for Education to try to make sure that the whole system is sending out the same message.

They have asked local areas to use their dynamic support registers and at risk of admission registers, to make sure they know who all the children are who should be on these. This includes children who have come home from out-of-area placements.

If your child has come home from a residential special school and you are not sure if they are on the dynamic support registers, contact your local CCG and ask for the Learning Disability and Autism lead who can explain the local process.



**My child is usually visited by a care professional at home, will this change?**

The government has some guidance for staff and services who provide care at home. You can read the full guidance [here](#). The most important points for families are:

- If the carer thinks they have coronavirus, they must follow

NHS guidelines and self-isolate;

- If your child may have coronavirus, they will work safely to reduce the chance of passing it on as much as possible;
  - They will have protective clothing such as masks and gloves;
  - They will use new items for each care activity, and will throw them away safely.
    - These should be tied in a bin bag and kept separately from any other rubbish for 72 hours (3 days) before throwing them away.
    - This means that if the virus is on the items, it will die and not spread further.
- If someone else in your home is self-isolating, and they can be kept away from your child, the carer will provide care as normal.
  - If they cannot be kept away from your child, your carer will work in the same way as if your child has coronavirus, to be on the safe side.

## Lockdown is affecting my child or young person's mental health and wellbeing; can they leave the house more often?

Government guidance has been updated to recognise that autistic people and others with similar conditions may be particularly strongly affected by the lockdown.

The guidance now says:

- If you need to leave your home to care for your own or someone you support's health, you can do;
- You can go to an outdoor space further away than your local area, for example to go to a preferred park;
- You can go out more than once a day;
  - Ideally it should say this in a care plan;
- You must still stay more than 2m apart from anybody else in that outdoor space.



## Further resources and support

### I am worried about my child's symptoms related to coronavirus

- Please visit the [NHS self-isolation advice website](#) for information.
  - If you are still worried, call NHS 111.

### I am worried about my child or young person's mental health

- Seek help from a professional, for example:
  - School or college who can help;
  - Your GP;
  - Local mental health services;
    - Visit your local CCG website, local offer website or the NHS website.
    - You should be able to find these through a search engine like Google.
- If your child is seriously mentally unwell or if they are at risk, call 999;
  - A mental health emergency should be taken as seriously as a physical health emergency.
  - For more advice on where to get support for a mental health crisis please see this [NHS page](#).
- Call the Young Minds for Parents and Carers helpline: 0808 802 5544
  - This is advice for parents and carers of children and young people aged up to 25;
  - Please be aware Young Minds do not provide any direct psychological services and cannot make referrals to mental health services.



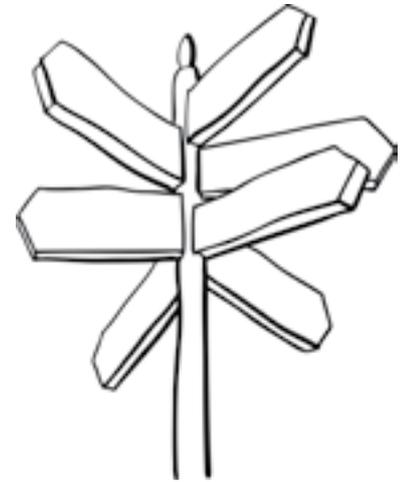
### I am worried about my own mental health and wellbeing

- Visit [how to look after your mental health and wellbeing](#) during the coronavirus outbreak;

- Visit [Every Mind Matters](#) for clear advice and steps you can take to look after your own mental health and wellbeing.

## My child or young person wants to access support independently

Anonymous support for children and young people can be found via helplines and websites such as:



- **Childline** for confidential counselling and support. It comforts, advises and protects:
  - Call 0800 1111 any time for free;
  - Have an [online chat with a counsellor](#);
  - Check out the [message boards](#).
- **The Mix** for the best confidential help, whatever the problem.
  - Call 0808 808 4994 for free – lines are open from 11am to 11pm every day;
  - Access the [online community](#);
  - [Email The Mix](#).
- **Shout** for free confidential crisis support at any time:
  - Text SHOUT to 85258 in the UK to text with a trained Crisis Volunteer;
  - Text with someone who is trained and will provide active listening and collaborative problem-solving.

## My child or young person is very anxious about coronavirus

- [Autistica, Coping with the uncertainty of COVID-19](#);
- Ambitious About Autism, [Uncertainty, Anxiety and the Coronavirus Pandemic](#).

## My child or young person is displaying challenging behaviour

- The Challenging Behaviour Foundation support:
  - Call 0300 666 0126;
  - Or email [support@thecbf.org.uk](mailto:support@thecbf.org.uk);
  - [Free downloadable resource sheets](#);
  - [Free resources about COVID19/ coronavirus](#).

## I need to explain coronavirus to my child or young person

- Carol Gray, [Social Story on Coronavirus](#) (National Autistic Society)
- Easy Read documents:
  - Public Health England, [Coronavirus \(COVID-19\)](#);
  - Public Health England, [Advice about the coronavirus](#);
  - Mencap, [a range of Easy Read guides](#) including self-isolation, social distancing, government guidance.
- [Books Beyond Words](#) (free to download)

## My question is not answered here

- National Autistic Society, [Autism Helpline](#) (currently running via webform)
- The Challenging Behaviour Foundation support:
  - Call 0300 666 0126;
  - Or email [support@thecbf.org.uk](mailto:support@thecbf.org.uk);
  - [Free downloadable resource sheets](#);
  - [Free resources about COVID19/ coronavirus](#).
- The Council for Disabled Children has pulled together some additional resources to support parent carers, children and young people as well as the latest government guidance on coronavirus.

## Appendix 1 – sources used in the document

Public Health England (2020), [Guidance for parents and carers on supporting children and young people’s mental health and wellbeing during the coronavirus \(COVID-19\) outbreak](#) [Updated 30th March 2020]

NHS England (2020), [Clinical guide for front line staff to support the management of patients with a learning disability, autism or both during the coronavirus pandemic – relevant to all clinical specialities](#) [Updated 24th March 2020]





## About the Council for Disabled Children

The Council for Disabled Children (CDC) is the umbrella body for the disabled children's sector in England, with links to the other UK nations. CDC works to influence national policy that impacts upon disabled children and children with Special Educational Needs (SEN) and their families. The CDC membership is made up of a variety of professional, voluntary and statutory organisations, including disabled young people and parent representatives. CDC's broad based membership and extensive networks of contacts provides a unique overview of current issues. It also enables us to promote collaborative and partnership working among organisations.

CDC hosts the following networks and projects:

- IASS Network
- Making Ourselves Heard
- Special Educational Consortium
- The Information, Advice and Support Programme
- Transition Information Network

[cdc@ncb.org.uk](mailto:cdc@ncb.org.uk) | [www.councilfordisabledchildren.org.uk](http://www.councilfordisabledchildren.org.uk)



Council for Disabled Children is hosted by the National Children's Bureau.