

INFORMATION SHEET



making a difference
to the lives of people with
severe learning disabilities

Coronavirus (COVID-19) information for families

We know that many families we are in touch with are very concerned about the impact of COVID-19. There are people who care for their family member at home who want to know what will happen if they become ill and cannot look after them. There are families who are concerned about the staff support their family member receives in the family home/their own home or with a provider organisation.

At CBF we understand that this is going to be a very stressful time for families of people with severe learning disability/autism and will be adding to the advice below as this situation develops. Please keep an eye on our [website](#) and [Covid 19 Information page](#) and we will do our best to support you as much as we can.

Government advice

As you know, the Government advice that we are receiving is changing constantly in response to the spread of the virus and this information will need to be updated as things progress. The most recent measures put out by the Government state that everyone must stay at home to stop the spread of the virus. You can only leave your home to shop for basic essentials; to do one form of exercise a day (alone or with people you live with); for any medical need (to visit pharmacies or deliver essential supplies to a vulnerable person); or to travel to and from work where completely necessary. We understand that this may have a significant impact on you and your family and suggest looking on our [Covid 19 Information page](#) for suggestions on how to care for your loved one under these circumstances.

What to do if you are at risk of COVID-19

If you are worried that you or someone you look after may be at risk, NHS 111 can offer direct guidance as they have set up an online [coronavirus helpline](#). You can also call 111, letting them know that you are a carer.

Getting help in Scotland, Wales or Northern Ireland:

- **Scotland:** call your GP surgery or call [111](#) if your surgery is not open
- **Wales:** call [111](#) (if available in your area) or call [0845 46 47](#)
- **Northern Ireland:** call [111](#)
- **If you have symptoms of coronavirus, you should stay at home for at least seven days. The NHS website has specific guidance on what action you should take and when, including tips on staying at home if necessary.**

However, at CBF we know that even the simple advice that people are being given, such as 20 seconds of hand washing, social distancing or self-isolating, may not be at all easy or even possible for someone who has a severe learning disability and/autism or the people who care for them. We have written to the Department of Health and Social Care asking them to provide more specific advice to families of people with learning disability and /autism and who display behaviours that challenge, and you can read the letter [here](#). We will share with you any response we receive.

CBF tips and suggestions

We don't have all the answers either but here are some things that may be helpful so that you are prepared as much as you can be.

Being prepared

Ask your social care provider to share their Covid-19 risk assessment and contingency plans and make sure they have thought about the circumstances for the person you support. Provider organisations are already identifying the risk to clients and categorising them into priority areas for support.

Create your own back-up plan for self-isolation:

- Make sure you have food and toiletries so you don't need to venture to the shops or so as little as possible: have an online shopping order ready with items you will need; ensure you have some "instant" meals (in the freezer or fridge) that can be served without much preparation e.g. microwave meals, tinned soups etc).

Think about activities you can do with your relative – have a supply of favourite DVDs, books, music, baking activities, puzzles and games ready, set up video calling to "meet" family and friends. Please see our [Covid 19 Information page](#) [please note that some resources are still in development and will be available at a later date].

Ask your social care support provider how they plan to manage their workforce. Tell them if you do not think that the plan will work for your situation, such as supplying agency staff who would not be familiar enough with someone's needs. Suggest what would work better. This is particularly important now that you will be accessing support during a lockdown.

Create your own back-up plan for staffing issues: who could help you or your family member if they or you became ill? Have you friends and family nearby who know your son /daughter/ relative well enough to step in and help?

Check with the local authority about their Emergency Plan. You can find their contact details [here](#). The local authority should also publish this plan on their website.

Link to government advice: <https://www.gov.uk/government/publications/covid-19-residential-care-supported-living-and-home-care-guidance/covid-19-guidance-on-residential-care-provision>

We are developing a resource on relevant guidance which will be available on our Covid-19 [information page](#) [please note that some resources are still in development and might not be available until a later date]

How do I protect someone I care for?

If you are caring for someone who is at high risk (has other health conditions) you should now be helping them self-isolate for 12 weeks. If they require health procedures that are routinely carried out, such as by a Community Nurse then think about how you can ensure that those people follow all guidance on hygiene.

Let your GP or medical professional know or remind them that you are a carer of someone with severe learning disabilities and behaviour that may challenge so if you become ill they will know immediately that the person you care for needs support.

Make sure that helpful tools like hospital passports and communication books are up to date and include what reasonable adjustments are required to enable your family member to receive the best possible care if they become ill.

Know the contact details of your acute hospital learning disability liaison nurses in your local hospitals so that if the person you support is admitted to hospital the team can be on hand to help doctors and nurses make the adjustments required and ensure they are getting good care.

Remember that you can request 'reasonable adjustments' to enable easier access to services for your relative. The Equality Act 2010 says that service providers, including hospitals and GP surgeries, must take reasonable steps to remove barriers which stop disabled people from having access to the same healthcare services as everyone else.

Health staff must also act in line with the Mental Capacity Act and if your son/daughter does not have capacity to consent they must make a best interest decision, properly consulting the family.

If your family member would be at risk if staff support was not available to you, you should regard this as a safeguarding risk and call your social services department as soon as the support is cancelled. "Safeguarding" is a formal process to protect vulnerable people from harm, abuse and neglect. The CBF can offer family carers support with safeguarding concerns.

If you employ your own staff you need to assess the risks to both your son/daughter and the staff who supports them. We are in the process of obtaining information on risk assessment for staff which we will make available on our Covid-19 [information page](#). Consider how you can mitigate these risks. Things to remember:

- you can cancel/limit/postpone annual leave,
- you can ask staff to supply information on their own dependents so you can assess how likely they are to be unavailable,
- you must pay staff for self-isolating as well as any sickness

Think through the situations you may face

Think about what you can put in place to help the person you care for to self-isolate because they are regarded as high risk or have symptoms of the virus.

Join our [Family Carers' Email Network](#) and share ideas with other families about what they are doing to support their family member.

Think of the best way to explain to the person about Covid-19. There are easy read resources by [Mencap](#), [RCNI](#), and [Books Beyond Words](#) to help them understand why things are happening.

Think about how you can help keep them safe, such as how can you make personal hygiene such as hand washing more fun by using songs and videos. See our activity guide on our Covid-19 [information page](#) [please note that some resources are still in development and will be available at a later date]

Care workers and other home help

If you employ your own staff, you need to be doing the exercise that all employers are doing and look at the risks for staff and how you can reduce these for your staff. There is advice for employers online at:

<https://www.gov.uk/government/publications/guidance-to-employers-and-businesses-about-covid-19>

If you have paid care workers, cleaners or other helpers coming into the home of the person you care for:

- Ensure that they are following stringent hygiene and infection control measures as set out by the NHS. If they are employed through an agency and you have any doubts, contact the agency to ask them about what protective measures they are taking.
- Talk to the person you care for about the [hygiene and infection control measures](#) they should expect someone coming into their home to follow. You should not be afraid to insist that these are followed.

- If possible, ensure soap and hot water is made readily available and towels are frequently changed.
- As well as following the steps above, if they are employed by an agency:
 - * speak to the agency about their contingency plans and how they plan to respond if any of their staff are affected
 - * if the care worker or other helper shows symptoms of coronavirus, do inform the agency. They will need to carry out a risk assessment and take steps to protect staff, their families and other clients from the virus. The agency should work with you to ensure that the person you care for is also safe.

Guidance for working family carers

If you're juggling caring with work, ask your employer about the measures they are putting in place to protect you as their staff member.

They should take account of the needs of staff who are caring for someone at high risk if they become ill with the virus and also that this person is dependent on you.

If you have been advised to 'self-isolate' by NHS 111 or a medical professional, or have decided to do so due to having symptoms, you must tell your employer as soon as possible. This does not need to be in writing. Your workplace's usual sick leave and pay entitlements will apply, even if you are working from home. The government has promised that Statutory Sick Pay (SSP) will be given from day one of self-isolation. You should check your contract of employment to see if your employer offers contractual sick pay on top. You may also be asked to certify your absence.

By law, for the first seven days of sickness, you are not required to provide medical evidence to your employer. However, after seven days, it is at the discretion of your employer to decide what evidence, if any, they need from you. Due to the unusual nature of the situation, the government has strongly advised that employers use their discretion. For workers that are ineligible for SSP, support will be available through Universal Credit and contributory Employment and Support Allowance.

As a carer, you already have the statutory right to [request flexible working](#). Also check with your employer if you are adequately set up to work remotely if this becomes necessary.

As an employee, you also have a statutory right to take a 'reasonable' amount of time off from work to see to an emergency or unforeseen matter involving your partner, child, parent, grandchild, or someone who relies on you for care. There is no fixed amount of time you can take off. The time off is unpaid unless your employer is willing to give paid time off as a contractual right. Also check your work policy on care leave.

Creating an emergency plan

It is a good idea for all families to create an emergency plan – for you and those you look after. Having a plan in place can help ease your worries if you are not able to care for those you look after at any point in the future and in the current circumstances if you became ill with Coronavirus.

In order to create an emergency plan that fits your needs, you will need to consider:

- details of 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 – this might include friends, family or professionals (you will need to consider who would be best suited to enter the home or service under current lockdown measures)
- details of any medication the person you look after is taking
- details of any ongoing treatment they need.

Involving others in the plan

You may be able to arrange help and support from family and friends but it can be reassuring to have the involvement of your local council or trust in case informal arrangements fall through.

If you have not had a carers assessment before this may be a good time to do so. You can contact social services to request this. Every carer who has an assessment should have been asked about emergencies and offered help to plan for them. If this has not been done, again this may be a good time to do so. We understand that it may be difficult to access a carers assessment at this time, but it is worth asking to see if this is possible.

Emergency 'carer card' schemes

Check if your area has an emergency carer card scheme.

In some areas there are emergency card schemes that have been set up for carers, often by the local council/trust or a local carers centre. This might be called:

- Carer card scheme
- Carers emergency card
- Emergency care scheme

In these instances, carers are usually asked to register and, with help from a skilled worker, draw up their emergency plans. The plans are held by the scheme which provides a 24-hour response service. Carers carry a card with the scheme's

telephone number and a unique identification number to avoid any personal details appearing on the card.

In some areas they are integrated with police, fire and ambulance services. In the event of an emergency, you or someone with you would call the scheme. An operator would look up your emergency plan and make arrangements for replacement care. This could involve contacting friends or family or putting in place professional help. Plans will have been shared with them so they know the individual requirements of the person requiring care, such as medication.

Please contact the CBF using info@thecbf.org.uk if you have useful information that we could add to this resource.

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