

# **Emergency planning for family carers, supporting an adult relative with learning disabilities, during the Coronavirus outbreak:**

**Ideas and information to help you through**



**Ideas and information to help others plan with families**

Free to download: <https://www.togethertomatters.org.uk/resources-and-information/>

**TOGETHER  
MATTERS**

## Emergency planning for family carers supporting, an adult relative with learning disabilities, during the Coronavirus outbreak

### Who is the information for?

<b>Family carers, other family members, friends and neighbours</b>	If it's the only option a family carer could use this on their own. But it will be much easier and create more of a network if others help. Siblings, aunts/uncles, family friends or neighbours could all help with emergency planning.
<b>Support workers, Personal Assistants (PAs), carers' organisations, support organisations, health and social practitioners</b>	If you have a paid role with family carers or people with learning disabilities, you could use this guide to help them find solutions and to make a plan. Use your knowledge of what is happening in your local council and/or local community. Provide paper copies of information (not all families have access to the internet or a printer).

### What is emergency planning?

It's all about getting as many things in place to reduce risks and having the right information to make things easier to cope with for your relative and yourself.

### How to use the information

How you use this information will depend on your situation (e.g. your age, health, support network, other caring responsibilities) and the type and level of support needed by your relative.

The best way to do any planning is to get others to help whenever possible. It's a lot to think about on your own. Talking with others will help to find solutions and share worries. If you don't have family, friends or paid workers who can help you sort out support, contact an organisation (such as a carers' centre or your local council to put you in touch with a social work team) to ask for support.

Use it as an aid to help you think things through and get your knowledge and ideas written down.

Use the links to get more information where it would be helpful to you.

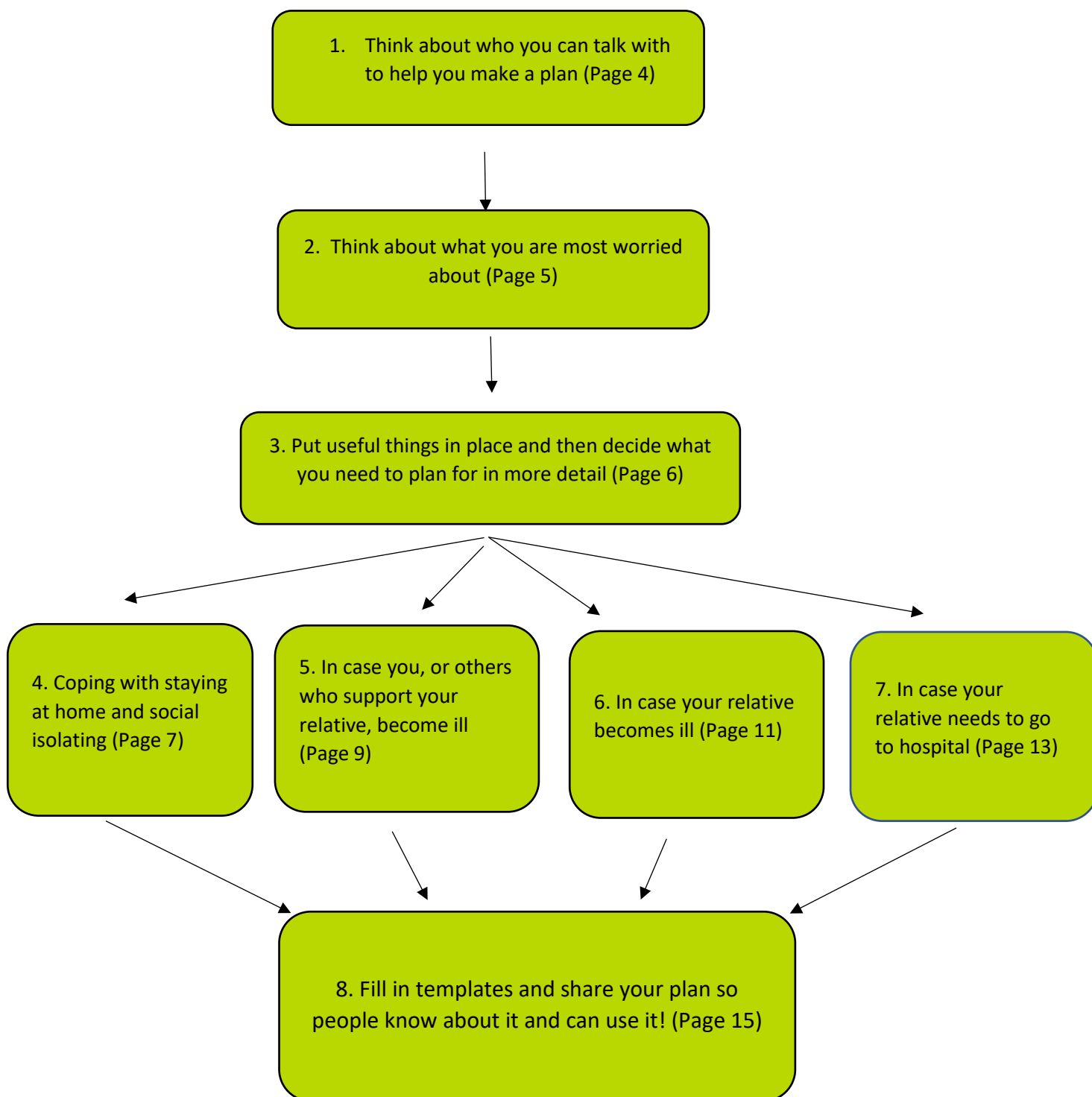
Take small steps and start with the planning you are most worried about.

Even if you end up not needing to use the plan during this crisis you can continue to develop your ideas in preparation for any future emergencies.

If you are supporting a family and not able to visit at the moment, you could do it over the phone: chat, ask questions and fill in templates for them (including the NHS Guide on Page 12). Then send them to other people to add information or to provide support. But take care to keep information safe and confidential.

## A quick guide to making a plan

Use this flowchart to give you a structure to think about what planning you want to do for this emergency.



# 1. Who can you talk to?

**To fill in this template on your computer, copy and paste into a Word document**

Think about who you know. You may feel reluctant to ask for help but lots of people are keen to help and have more time than usual in the current situation. Use the table below to think about people who can:

- help you with making plans and getting your plan written down;
- give you practical and/or emotional support and help you get the information you need.

Don't worry that you don't know people on each line. Your support network will grow as you plan.

	Who	Phone number/email
Other people in your household		
Family members		
Friends and/or neighbours		
Local carers' organisation (to give you advice)- link on Page 7		
Local learning disability and autism groups and organisations		
Local advocacy and self-advocacy groups		
Care and support organisations and services that help you or your relative		
Local community organisations and places (social, religious, etc)		
Local community hubs/mutual aid groups set up to help in this crisis		
GP (yours and your relative's)		
Other healthcare workers you or your relative see, including the Learning Disability Community Health Team		
Social work and other teams in Adult Social Care or transition service		
Learning Disability Liaison Nurse (in acute hospitals) – see Page 12		
National learning disability or carers' organisations (some are on Page 18)		
Other		

## 2. In this Coronavirus outbreak what emergency are you most worried about?

*To fill in this template on your computer, copy and paste into a Word document*

Think about what you are most worried about so that you can share this with others and make sure your planning helps to put things in place to find solutions.

If you are supporting someone to plan this is a chance to talk to them about what is most important to them.

What I am most worried about	What might help	Who can I ask to help

### 3. Put helpful things in place now

*To fill in this template on your computer, copy and paste into a Word document*

Some ideas	This is done	I need to do this	What I will do/what I will ask others to do
<p><b>Let people know you care for someone.</b>            Are you registered with a local carers' scheme? If so, have the card in your wallet/by the front door.            Do you have a Message in a Bottle? Check the information is up to date.            Alert your GP and your local authority to the fact you are a family carer. Let them know if you are caring on your own.</p>			
<p><b>Sort out phone numbers and put them on one sheet.</b>            You can use the list on Page 4 or the template in Section 8 of this guide. This is a handy reference list for you and others.</p>			
<p><b>Share your list of phone numbers with relevant people.</b> If they also have each other's phone numbers they can liaise about providing help if you become ill. Give your key contacts the phone numbers of the social work team/Adult Social Care. Give your local authority and/or GP the numbers of your key contacts.</p>			
<p><b>Think about how your relative could call for help and practise with them</b> (if you are the only two in the household). You could have a pre-set number on a phone, show them how to knock on a neighbour's door or ask someone (with your house keys) to phone each day to check on you both.            If you have a Telecare button, does your relative know how to use it?</p>			
<p><b>Gather information about your relative that would help others support him/her</b> (see list on Page 17). Use the templates in Section 8 to write new information. Look at the NHS COVID-19 Grab and Go Guide (link on Page 12) and start filling in the information you have.</p>			
<p><b>Think about using WhatsApp</b> – to do this you need a smartphone (a mobile on which you can use the internet and apps). It's easy to use and is a way for a group of people to talk or message together and/or arrange support. For easy instructions on using it:  <a href="http://www.learningdisabilityengland.org.uk/wp-content/uploads/2020/03/whatsapp-an-easy-read-guide-DRAFT-v2.0.pdf">www.learningdisabilityengland.org.uk/wp-content/uploads/2020/03/whatsapp-an-easy-read-guide-DRAFT-v2.0.pdf</a></p>			

## 4. Coping with staying at home and social isolating

As a carer it's very important you ask for the help you need with staying at home and social isolating in order to keep your relative and yourself safe and well. The government has produced guidance that may answer some of your questions about this.

<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>

Over the past weeks lots of useful information and support systems have been developed to help people stay at home. Much of the information and access to support is on the internet. If you don't have access to the internet, ask other people to look at it and give you the details or print it off and post it to you. A local carers' organisation should be able to help you with this if you don't have family or neighbours. Use this link if you need to find your nearest carers' organisation

<https://www.carersuk.org/help-and-advice/get-support/local-support>

Information and ideas to help you cope with staying at home and social isolating are grouped under three headings:

- i) Getting the practical help you need
- ii) Getting support with caring
- iii) Helping your relative to cope with staying at home

### i) Getting the practical help you need

If you need practical help with things such as shopping, collecting prescriptions, topping up gas/electricity meters or dog walking, there seem to be sources of help in all local councils. Councils have details of how this is being organised on their website and/or are delivering information to households. There are also local voluntary groups that may be able to help with a range of practical tasks. You can find out about these groups by using this link <https://covidmutualaid.org/> but if you need help to get the contact details then phone your local council or carers' organisation.

### ii) Getting support with caring

You may have taken on more caring responsibilities because of the closure of support services or paid carers not being able to come to your home and/or your relative may be struggling with staying at home and changes to their support. In Section 5 there are ideas to help you get alternative or additional support should you become ill, but this information also applies if you are struggling to cope with the lock down and giving additional care to your relative.

### iii) Helping your relative to cope with staying at home

	Resources to help
<b>Understanding Coronavirus</b> Your relative may need help to understand about coronavirus, why they are being told to stay at home and that the changes are not for ever and will pass. There is lots of easy-read information explaining different aspects of the virus.	<a href="https://www.keepsafe.org.uk/coronavirus-info-1">https://www.keepsafe.org.uk/coronavirus-info-1</a>  <a href="http://www.openingdoors.org.uk/uploads/images/486.pdf">http://www.openingdoors.org.uk/uploads/images/486.pdf</a>

	Resources to help
<p><b>Daily structure</b></p> <p>Create structure for the day. You and your relative could make a plan together for the coming day so they feel they have some choice and control. Some things that could be included are:</p> <ul style="list-style-type: none"> <li>• What we'll make for lunch</li> <li>• Exercise and/ or daily walk</li> <li>• Jobs around the house</li> <li>• Something to cook, paint or make, favourite TV show</li> <li>• Who to speak to on the phone or video chat</li> </ul>	<p>In the link above for Opening Doors there are ideas for planning your day.</p> <p><a href="https://www.sclid.org.uk/wp-content/uploads/2020/04/You-Can-Do-It-Being-Active-and-Keeping-Better-Booklet.pdf">https://www.sclid.org.uk/wp-content/uploads/2020/04/You-Can-Do-It-Being-Active-and-Keeping-Better-Booklet.pdf</a></p>
<p><b>Managing anxiety</b></p> <p>Think about what helps your relative to manage their anxiety. The links gives ideas for your relative to use or for someone to talk through with them.</p>	<p><a href="https://www.peoplefirstdorset.org.uk/news">https://www.peoplefirstdorset.org.uk/news</a></p> <p><a href="https://www.sclid.org.uk/wp-content/uploads/2020/04/Feeling-Anxious-about-Coronavirus-Booklet.pdf">https://www.sclid.org.uk/wp-content/uploads/2020/04/Feeling-Anxious-about-Coronavirus-Booklet.pdf</a></p>
<p><b>Being connected</b></p> <p>Who could your relative speak to so as to be more connected with friends and/or family (and perhaps to talk about their worries)? Who could you talk to?</p>	
<p><b>Daily exercise</b></p> <p>The government's initial guidance was to only go out once a day for exercise. On April 8<sup>th</sup> this was amended to take into account the difficulties this would cause for some people, including 'where individuals with learning disabilities or autism require specific exercise in an open space two or three times each day'. (further information in link).</p>	<p><a href="https://www.gov.uk/government/publications/coronavirus-outbreak-fags-what-you-can-and-cant-do/coronavirus-outbreak-fags-what-you-can-and-cant-do">https://www.gov.uk/government/publications/coronavirus-outbreak-fags-what-you-can-and-cant-do/coronavirus-outbreak-fags-what-you-can-and-cant-do</a></p>
<p><b>Understanding changes in behaviour</b></p> <p>You may find that your relative's behaviour changes with staying home. This could be a result of changes in routine, feeling anxious or picking up on your concerns. The Challenging Behaviour Foundation have produced information with useful suggestions such as giving someone as much control as possible over things that can be in their control, building a new routine and asking for external help through a social worker or Learning Disability Health Team. They also stress the need to be aware that behaviour changes may be caused by physical health problems.</p>	<p><a href="https://www.challengingbehaviour.org.uk/learning-disability-assets/3challengingbehavioursupportingyourlovedoneathome.pdf">https://www.challengingbehaviour.org.uk/learning-disability-assets/3challengingbehavioursupportingyourlovedoneathome.pdf</a></p> <p>There is also a visual version</p>
<p><b>Your health and well-being</b></p> <p>It's important to look after your own well-being to reduce anxiety and exhaustion. Try to build small things into your day that you enjoy. Is there something relaxing you can do together such as looking at old photographs and making a memory box.</p>	<p>If you would like information about making a memory box or life story book, email <a href="mailto:christine@togethertomatters.org.uk">christine@togethertomatters.org.uk</a></p>
<p><b>Access to advocacy</b></p> <p>This link will help you if you or your relative would like to know about your rights because of changes to the Care Act. It also tells you about getting support from local advocacy services.</p>	<p><a href="https://qualityadvocacy.org.uk/wp-content/uploads/2020/04/Easy-Read-Coronavirus-Facts-About-Advocacy-and-Rights.pdf">https://qualityadvocacy.org.uk/wp-content/uploads/2020/04/Easy-Read-Coronavirus-Facts-About-Advocacy-and-Rights.pdf</a></p>



## **5. In case you, or other people who support your relative, become ill (including going to hospital)**

In the current situation this can feel difficult to get your head around especially if you are the main or only carer for your relative. But don't put it off: have options in place in case you become ill and/or need to go into hospital. It is hard to think clearly when you are unwell.

If you and your relative with a learning disability are living in the same house you should consider the government's advice for carers of someone who is vulnerable to COVID 19, should they become ill. Firstly, could your relative move out of your home, to stay with family, friends or elsewhere during the isolation period? If this is not possible then the advice is to stay away from them as much as possible. It may be difficult to follow this advice and, if this is the case, you should consider contacting the local authority social work team to find out what can be put in place. The government's guidance can be found in the following link under 'If you have a vulnerable person living with you' <https://www.gov.uk/government/publications/covid-19-stay-at-home-guidance/stay-at-home-guidance-for-households-with-possible-coronavirus-covid-19-infection>

Ideas for your plan in case you get ill are grouped under three headings:

- i) Getting back-up support for your relative
- ii) Having information for other people stepping into a support role with your relative
- iii) Getting the care you need

### **i) Getting back-up support for your relative**

Your approach to this will depend on different factors such as the nature and level of support your relative needs, how easy or difficult they find it to be supported by someone new and how many people you have in your support network. If your relative needs lots of support (for example, with their personal care, behaviour or anxiety) contact Adult Social Care and ask them about the support that would be available should you become ill. You could also ask if some support could be funded/put in place now to help prevent you from becoming ill.

There are three main places you can look to for organising and obtaining support. Your final plan may involve a combination of support from different places.

- You may want to arrange back-up support from family, friends and other people you already know. Talk to them now: ask them how they might be able to support your relative and what they would need to do this.
- If your relative is already receiving support from an organisation (either at home, such as personal care, or elsewhere, such as residential respite) they should have already been in touch with you to tell you their arrangements and how they can help you. If they haven't contact them to find out. Make sure their details are in the list of contacts you've compiled in the template in Section 8. If your relative receives a direct payment this could be used differently for example, to pay a family member (information, covering both children and adults at <https://www.specialneedsjungle.com/care-coronavirus-using-direct-payments-pay-family-members-care/> )

- You may want or need to ask your local authority and/or your Clinical Commissioning Group (if your relative receives Continuing Healthcare) to help arrange support. If you have not heard from a social worker, or someone similar, and are worrying about how your relative will be supported if you became ill, get in touch with them now so you are on their radar and you know the possible options. If you don't know how to get in touch with them use this link <https://www.gov.uk/find-local-council>

After you have gone through the different options, fill in your preferred options in the template on Page 15. There isn't a guarantee this will happen, but should help others to sort out good support.

## ii) Having information for other people stepping in to support your relative

The next thing to think about is what information you need to give to someone should they need to step into a support role for your relative. There are a number of ways to gather this information:

You may already have information written down in a care and support plan, a recent assessment, a person-centred plan, a communication passport or a hospital passport. Have a look at these and see which of them gives a good picture of your relative's needs. Then put the useful ones somewhere easy for others to access or share them, whilst respecting your relative's confidential information. On the other hand, you may need to select the most useful information from a few documents and create something new. Talk to your relative about the information they want others to have about them, if they would like, and are able, to do this.

If you provide a lot of personal and practical support to your relative, you should make a list of all the essential tasks that a supporter would need to know about. There may be additional things that you think are desirable but start by getting the essential list written down. Once this is done, and if you feel able, you can make a 'desirable' list. You could go through the day and think of the different essential tasks and list them on the template on Page 17. Think about who else could do them and/or how they could be done differently.

Another way of gathering information is to think about what helps to keep your relative safe and healthy and what helps them to feel good about themselves (this can be very important when someone is feeling anxious). There is a template for this on Page 17, and also one for writing down what helps your relative to have a good day and what may lead to a bad day.

Fill in any of the templates on Page 17 that you think would be useful to help other people support your relative.

## iii) Getting the care you need if you are ill

And finally, you need to plan for how you will be cared for and supported if you become ill. You may neglect to care for yourself properly because of your caring responsibilities. But you need to take on board that caring responsibilities can increase your exhaustion and affect your ability to recover. Err on the side of caution in seeking medical advice and don't take any risks with your health.

Government guidance on looking after your health is to '*Speak to the NHS if you feel you cannot cope with your symptoms at home, or your condition gets worse, or your symptoms do not get better after 7 days. Use the [NHS 111 online](#) coronavirus (COVID-19) service. If you do not have internet access, call NHS 111. For a medical emergency dial 999*'.

## 6. In case your relative becomes ill

Your approach to this will depend on your relative's needs and understanding. You know your relative well so these ideas are suggestions that may be helpful but always use your knowledge and understanding of your relative and any clinical advice you receive from your GP, NHS 111 or other health services. Use your past experiences of your relative becoming ill and/or what you have read about COVID 19 to think about what might help them to cope with feeling unwell. Be led as much as possible by your relative and use the resources below to help them understand what is happening to them.

When someone has a learning disability and/or autism it can be much more difficult to know what is wrong, understand their symptoms and the level of pain they are feeling. This is why health services are expected to remove barriers and/or make changes in the way they do things to ensure a person's disability does not prevent them from getting the assessment and treatment they need. This is called making 'reasonable adjustments' and is part of the Equality Act 2010. This is a useful phrase to know in case you feel a different approach is needed because of your relative's learning disability and/or autism (see NHS guidance for frontline staff on Page 13).

Don't sit at home and worry about whether you should ask for clinical help: it is better to be overcautious for the reasons given above. Let a health practitioner know your relative is unwell and you suspect it might be COVID-19. This might be their GP or someone else who knows them at the practice or a health practitioner on the Community Learning Disability Health team. Also let them know if your relative has any underlying health problems, particularly respiratory problems (such as asthma), diabetes or is taking any immunosuppressant medicines.

Your relative may become ill with something other than Coronavirus. The government's advice is to not put off seeking advice or treatment for other health problems.

Talk with people on your list on Page 4 about who can help you if your relative becomes ill if you think it would be difficult to cope on your own or with the current level of support you have. If your relative becomes ill let others know. You may need their help now and, even more so, if you have become infected. It is best to give people some warning that you may be in need of a lot more help.

Be ready to call 111 to talk about your relative being admitted to hospital. If you are struggling to cope or your relative is struggling with their illness, call 111, your GP or another health practitioner to let them know. It may take a while to get an answer so it's better to be cautious rather than delay it. If they are struggling to breathe you should call 999.

What you might want to think about	Information and resources to help
<p><b>Making sense of feeling ill</b> Help your relative to understand what is happening to them: there are lots of helpful resources on the internet</p>	<p><i>Beating the Virus</i> is a booklet with simple drawings that could help you talk to your relative about symptoms and being unwell at home: <a href="https://booksbeyondwords.co.uk/coping-with-coronavirus">https://booksbeyondwords.co.uk/coping-with-coronavirus</a></p>
<p><b>Help for you to understand</b> The BBC film clip summarises the important points about caring for someone in the same house.</p>	<p><a href="https://www.bbc.co.uk/news/av/health-52161088/coronavirus-how-do-you-care-for-someone-at-home">https://www.bbc.co.uk/news/av/health-52161088/coronavirus-how-do-you-care-for-someone-at-home</a></p>
<p><b>Coping with feeling unwell</b></p>	<p>The advice from the NHS is to drink plenty of fluids (urine should be pale and clear), lie down and rest and take pain relief (paracetamol). Check with a health practitioner if you are not sure if it is safe for your relative to take paracetamol.</p>

What you might want to think about	Information and resources to help
	Your relative may need things to distract them and lots of reassurance to help them feel less agitated or worried.
<p><b>Temperature and swab taking</b> Easy-read information has been written to help people with temperature taking and swab taking. Practise temperature taking whilst someone is well so they get familiar and so you know their usual temperature range (and note this).</p>	<p>Temperature taking: <a href="https://www.challengingbehaviour.org.uk/learning-disability-assets/temperatureinformationsheet.pdf">https://www.challengingbehaviour.org.uk/learning-disability-assets/temperatureinformationsheet.pdf</a></p> <p>Swab taking: <a href="http://www.openingdoors.org.uk/uploads/images/495.pdf">http://www.openingdoors.org.uk/uploads/images/495.pdf</a></p>
<p><b>Keeping a diary of their illness</b> Use a notebook to record details of their health (see examples in list). It's hard to remember details over a number of days so this information will help you when talking to a doctor or nurse, or help others who are supporting you. Take to hospital along with COVID-19 guide below.</p>	<ul style="list-style-type: none"> <li>• Contact with others with COVID-19 symptoms/ diagnosis</li> <li>• Usual temperature range</li> <li>• Regular recording of temperature whilst unwell</li> <li>• If/when a new cough developed</li> <li>• Date/time of pain relief</li> <li>• Breathing pattern</li> <li>• How they seem to you</li> </ul>
<p><b>Being ready for hospital</b> <b>*It is never too soon to get ready for hospital. The NHS COVID 19 Grab and Go Guide will help clinicians to make quick and effective decisions about your relative's treatment so make sure this is filled in.*</b></p> <p>Easy-read information has been written to help explain what will happen in hospital during treatment for COVID 19. If you think your relative would be concerned about meeting doctors and nurses in protective equipment there is an easy-read sheet about PPE to help with this.</p> <p>Learning Disability Liaison Nurses have a key role in Acute Hospitals to help people with learning disabilities cope with hospital care and help doctors understand about caring for people with learning disabilities.</p> <p>Prepare a bag for hospital</p>	<ul style="list-style-type: none"> <li>• <b>NHS COVID 19 Grab and Go Guide</b> <a href="https://www.learningdisabilityengland.org.uk/wp-content/uploads/2020/04/NHS-Covid-19-Grab-and-Go-LDA-Form-A4-v2.pdf">https://www.learningdisabilityengland.org.uk/wp-content/uploads/2020/04/NHS-Covid-19-Grab-and-Go-LDA-Form-A4-v2.pdf</a></li> <li>• Hospital passport: make sure all details are correct e.g. medication dose. For information about passports and a template go to <a href="https://www.mencap.org.uk/advice-and-support/health/health-guides">https://www.mencap.org.uk/advice-and-support/health/health-guides</a></li> <li>• Easy-read information about going to hospital: <a href="https://www.keepsafe.org.uk/resources/why-we-wear-ppe-poster">https://www.keepsafe.org.uk/resources/why-we-wear-ppe-poster</a></li> <li>• <a href="http://www.learningdisabilityengland.org.uk/wp-content/uploads/2020/03/Hospital-and-coronavirus-widgit.pdf">http://www.learningdisabilityengland.org.uk/wp-content/uploads/2020/03/Hospital-and-coronavirus-widgit.pdf</a></li> <li>• Find out the name and/or number of the Learning Disability Liaison Nurse for your hospital and for others in your area as people may not always go to their local one. If this is difficult to find (and not every hospital has one) look for the number of the Safeguarding team and ask them who you should speak to.</li> <li>• Use the checklist in the next section.</li> </ul>

## 7. In case your relative needs to go to hospital

Think ahead about the possibility of your relative needing to go to hospital so that you, and others in their support network, are practically and emotionally prepared. Don't wait until your relative becomes ill as Coronavirus affects everyone differently and they may suddenly need to go to hospital. The things you put in place beforehand will help medical staff know more about your relative and therefore the best way to treat them.

If NHS 111 advises you that your relative needs to be admitted to hospital, they will arrange for an ambulance to take them. If this happens let a key person in your support network know and ask them to tell others. At this time contact the Learning Disability Liaison Nurse (see Page 12) or the Safeguarding team to inform them too.

Your relative should be able to have a family member or paid carer with them in hospital if they need help to get the right treatment. Plan beforehand who would be the best person to do this (e.g. someone who is good at supporting your relative, who would be good at speaking up for them and is healthy and not in the at-risk categories).

It is helpful to know that NHS England's guidance on visitors to hospital was changed on April 8th to say there are 'exceptional circumstances where one visitor – an immediate family member or carer – will be permitted to visit'. One of these circumstances is that 'you are supporting someone with... a learning disability or autism, where not being present would cause the patient to be distressed.' Take a copy with you in case clinicians are unfamiliar with the guidance.

<https://www.england.nhs.uk/coronavirus/publication/visitor-guidance/>

It may be helpful to think about what your relative might need when arriving at the hospital and being assessed for treatment (e.g. drink, snack, comforting object). At the point when someone is very ill they are unlikely to need things to do but may benefit from items that help them cope with the hospital environment during treatment (e.g. sunglasses or eye mask to block out bright lights, headphones to block out noise). You may want to think ahead to the time when they are recovering as they may find it helpful to have something to distract them.

The NHS has written guidance for frontline staff caring for patients with a learning disability or autism. It includes the duty to listen to parents/carers, make reasonable adjustments (see Page 11), understand an individual's response to pain and seek specialist support if necessary. Read this guidance to help you plan for a hospital admission and preferably print a copy for the hospital bag. This should provide reassurance and be a useful checklist for the person supporting your relative in hospital. There is also an easy-read version. [https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0031\\_Specialty-guide\\_LD-and-coronavirus-v1\\_-24-March.pdf](https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0031_Specialty-guide_LD-and-coronavirus-v1_-24-March.pdf)

You may be very worried about your relative would cope with the hospital environment and medical procedures, particularly as you or another person may not be able to be with them all the time. A helpful booklet, *Jack Plans Ahead for Coronavirus: a guide for family and carers* (<https://booksbeyondwords.co.uk/coping-with-coronavirus>), has been written to explain some of the complex issues regarding people going to hospital for treatment. It covers the difficult issue of receiving treatment in the unfamiliar environment of an intensive care unit and sensitively explores the alternative decision of remaining at home through the story of Jack. 'This is a very complex

decision and should be discussed with as many people as possible, in advance: Jack himself (if he wants to, and is able to be involved), his family, staff, anyone else who knows him well and has his best interest at heart, and his GP who will know about Jack’s risk factors (such as underlying health conditions.)’ The booklet also has ideas for preparing for hospital and creating a One-page Profile.

### Checklist to take to hospital

**To fill in this template on your computer, copy and paste into a Word document**

Have a printed copy of this list in the hospital bag so that your relative’s supporter and/or hospital staff know what they have with them. Check it one last time before the ambulance.

	My relative needs this	It’s packed
NHS COVID 19 Grab and Go guide <a href="https://www.learningdisabilityengland.org.uk/wp-content/uploads/2020/04/NHS-Covid-19-Grab-and-Go-LDA-Form-A4-v2.pdf">https://www.learningdisabilityengland.org.uk/wp-content/uploads/2020/04/NHS-Covid-19-Grab-and-Go-LDA-Form-A4-v2.pdf</a>		
Diary you have kept of their illness		
Hospital passport		
Names and numbers of essential contacts		
NHS information (to help person supporting your relative to advocate for them): Guidance for front-line staff and Visitor’s guidance (see Page 13		
Small overnight bag		
Medication (including information about dosage)		
Equipment, aids, posture support and incontinence pads (if used)		
Personal items such as pyjamas, spare underwear and socks, toothbrush and toothpaste		
Bottle of water/snack (non-perishable)		
Phone (this could have photos of people they are close to) and charger		
Communication aids, glasses, hearing aid		
Tablet (if your relative uses one) charger and headphones		
Items, such as headphones, eye mask, if they would help to cope with the hospital environment		
An item that would be comforting/photo of family or friend		
Other items		

**8. Fill in templates and share your plan (so others know about it and can use it)**

*To fill in these templates on your computer, copy and paste into a Word document*

**Your relative's details**

Name	
Address	
Telephone number	
Date of birth	
NHS number	

**Your details**

Relationship to person above	
Name	
Address	
Telephone number	

**Main person/people who could help make arrangements and advocate for your relative in an emergency (in addition to yourself). Give them a copy of your plan.**

Name	Relationship to your relative	Telephone and email

**What do you think would work best if you became ill and your relative needed support?**

What we would like to happen	What needs to be put in place to make this work	Who to talk to

**Is there anything you and your relative would not want to happen/anyone not to be contacted?**

**Anything else you would like to add?**

--

**My key contacts** (decide which ones need a copy of your plan)

Name	Organisation/ relationship to relative	Phone number	Email address/ where they live (if neighbour)	How they can help (e.g. key holder, have my relative to stay/stay at house with them)

**Which of these does your relative have? (Put a copy with this plan)**

	Yes	No
<b>COVID 19 Hospital Summary</b>		
<b>Hospital passport</b>		
<b>Communication passport</b>		
<b>Person-centred plan</b>		
<b>Care and support plan</b>		
<b>Other</b>		





## Resources and organisations

The government website for advice is <https://www.gov.uk/coronavirus> . Some of their advice is in easy read and different languages.

Organisation	Contact details	Information
Books Beyond Words	<a href="https://booksbeyondwords.co.uk/coping-with-coronavirus">https://booksbeyondwords.co.uk/coping-with-coronavirus</a>	Short books with drawings to support people to have a better understanding of their experience of coronavirus.
Carers UK	<a href="https://www.carersuk.org/help-and-advice/coronavirus-covid-19/coronavirus-covid-19">https://www.carersuk.org/help-and-advice/coronavirus-covid-19/coronavirus-covid-19</a>	Regularly updated information for carers and people they support. Has a link to find your local carers' centre.
Challenging Behaviour Foundation	<a href="https://www.challengingbehaviour.org.uk/">https://www.challengingbehaviour.org.uk/</a>	Resources for family carers of people with severe learning disabilities. Very useful activity ideas and legal advice.
Downs Syndrome Association	<a href="https://www.downs-syndrome.org.uk/coronavirus-covid-19/dsa-resources/">https://www.downs-syndrome.org.uk/coronavirus-covid-19/dsa-resources/</a>	Wide variety of resources including booklet 'Supporting young people and adults through times of change'. Also, activity ideas.
HFT Family Carer Support Service	<a href="https://www.hft.org.uk/our-services/family-carer-support-service/">https://www.hft.org.uk/our-services/family-carer-support-service/</a> Gives advice to family carers by email: <a href="mailto:familycarersupport@hft.org.uk">familycarersupport@hft.org.uk</a> or call 0808 801 0448 (leave message)	Helpful explanation of the Mental Capacity Act and best interest decisions <a href="https://www.hft.org.uk/our-services/family-carer-support-service/fcss-updates/mental-capacity-act">https://www.hft.org.uk/our-services/family-carer-support-service/fcss-updates/mental-capacity-act</a>
Learning Disability England	<a href="https://www.learningdisabilityengland.org.uk/">https://www.learningdisabilityengland.org.uk/</a>	Sharing information and resources from a wide variety of places. Holding useful webinars (available to listen to). Helping people to be connected with each other.
Learning Disability Wales	<a href="https://www.ldw.org.uk/">https://www.ldw.org.uk/</a>	Resources and guidance, including information specific to Wales.
National Autistic Society	<a href="https://www.autism.org.uk/services/helplines/coronavirus.aspx">https://www.autism.org.uk/services/helplines/coronavirus.aspx</a>	Wide variety of resources for autistic people and their families.
Scottish Commission for Learning Disabilities	<a href="https://www.sclld.org.uk/information-on-coronavirus/">https://www.sclld.org.uk/information-on-coronavirus/</a>	Scottish Government guidance and lots of other information. Link to <i>COVID-19 Guided Self-help Booklet Series</i> created by University of Glasgow (developed for people with mild to moderate learning disabilities).
SIBS	<a href="https://www.sibs.org.uk/">https://www.sibs.org.uk/</a>	Information for brothers and sisters
Together Matters	<a href="https://www.togethertomatters.org.uk/resources-and-information/">https://www.togethertomatters.org.uk/resources-and-information/</a>	Resources to help people plan for emergencies as well as more generally, using Thinking Ahead and I'm Thinking Ahead guides.

This information has been developed by Together Matters. You can download further copies from the website: [www.togethertomatters.org.uk/resources-and-information](http://www.togethertomatters.org.uk/resources-and-information)

The situation regarding Coronavirus is frequently changing so please check on the websites of national organisations for up-to-date information.

Together Matters has produced this booklet with greater haste than would usually be the case so please forgive any errors or omissions. If you find any errors please let us know and we will do our best to correct them.

We would welcome any feedback about the content and would love to hear how you have used it and whether anything has been particularly useful. We are always keen to share your stories with others and learn from you to develop further resources.

Email [Christine@togethertomatters.org.uk](mailto:Christine@togethertomatters.org.uk) with feedback, to sign up for our occasional newsletters or to find out how we can help you with planning for the future, including planning for emergencies.

*Emergency planning for family carers, supporting an adult relative with learning disabilities, during the Coronavirus outbreak* was written by Christine Towers.

April 2020