



Beyond Words
empowering people through pictures



Jack Plans Ahead for Coronavirus: a guide for family and carers

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Anyone can get ill with coronavirus (COVID-19). Although most people will recover, some people will die. It is important to plan ahead, so that you don't have to make the most difficult decisions at a time of huge distress and time pressure.

To help these difficult conversations, in this guide, we are talking about Jack, who has learning (intellectual) disabilities. He shares a flat with his friend Thomas. Support workers come in every day to help them; Gloria is their favourite support worker. His elderly mother and brother live nearby.

For some people it is entirely appropriate that they go into hospital, including intensive care. For others, it is better to stay at home, in a familiar environment with familiar people, even if that means that they die at home. Jack is most likely to benefit from hospital if he is usually fit and well.

See the latest guidance from NHS England: <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/C0166-Letter-DNACPR.pdf>

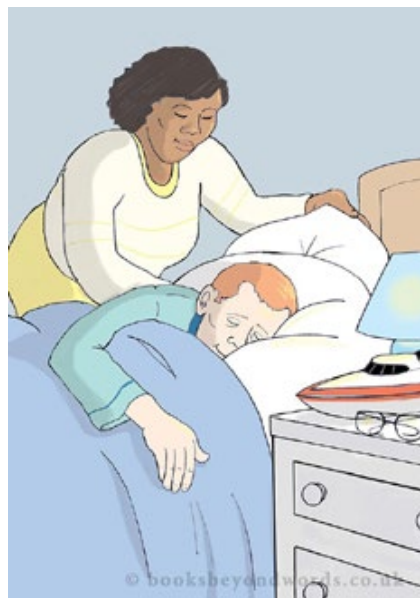
The health of some people who have a learning disability and/or a diagnosis of autism may be at risk from the presence of co-existing physical conditions and also from inequities in access to and delivery of appropriate and timely assessment and treatment for physical health conditions.

It is imperative that decisions regarding appropriateness of admission to hospital and for assessment and treatment for people with learning disabilities and / or autism are made on an individual basis and in consultation with their usual carers. Treatment decisions should not be made on the basis of the presence of learning disability and/ or autism alone.

“If I get ill with coronavirus...” **Do you want to go to hospital?**

Should Jack go into hospital when he gets ill with coronavirus? It is a good idea to think about this before he gets ill. It 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, the 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).

It is not an easy decision. If Jack is taken to hospital, he will almost certainly be without the people he knows and trusts – and if he dies, he will die without having a familiar person around. Jack has good communication skills, but he may not be able to communicate his needs and wishes, because he is so ill. He is likely to be frightened, too.



These are the things to consider:

- Is Jack in an “at risk” group?
 - Is he elderly and frail? Remember that for some people with learning disabilities, the physical process of ageing is quicker.
 - Does he have other health problems such as diabetes or heart disease, or respiratory conditions? That means

he is much less likely to benefit from intensive care, ventilation etc.

- How would Jack cope with being in hospital on his own?
 - What are the reasonable adjustments that Jack would need in hospital? Would they be achievable at this time?
 - Would it be possible to support Jack virtually? Is he able to use a phone or tablet?
 - Are there some aspects of hospital that Jack could cope with, but not others? (For example, would he be OK on an ordinary hospital ward but terrified in intensive care?)
 - If Jack would be extremely distressed in hospital, or behave in ways that are disturbing for him and others (such as wandering, swearing or shouting, touching other people's equipment), are there acceptable ways in which to make a hospital stay possible – for example, mild sedation?
- Would Jack prefer to stay at home, even if that means he could die there – but knowing that the person looking after him is probably someone familiar?
- If he does stay at home, who would look after him? How will Gloria and her colleagues cope? What are the possibilities? What support is available?

Here are some words you could use to talk with Jack about "What if..."

Lots of people are getting sick with coronavirus. Most people get better, but some people die.

The people who are the sickest need to go into hospital. Some people get better in hospital. But some people die in hospital.

When people go into hospital, they are not allowed any visitors, because of the coronavirus.

I hope you won't get sick and you won't need to go into hospital. But it is a good idea for all of us to think about what we want, just in case. This is what we are going to talk about.

I have thought about it too. I have talked with my family about what I want, just in case. I have written it down. Now I am going to help you to write it down, too.

If you were ill with coronavirus, would you want to go into hospital? The doctors and nurses will look after you. They will try and make you better. But your mum and your brother can't visit. Gloria can't be with you in hospital. Thomas can't visit either. They will all talk to you on your phone. You can Skype them.

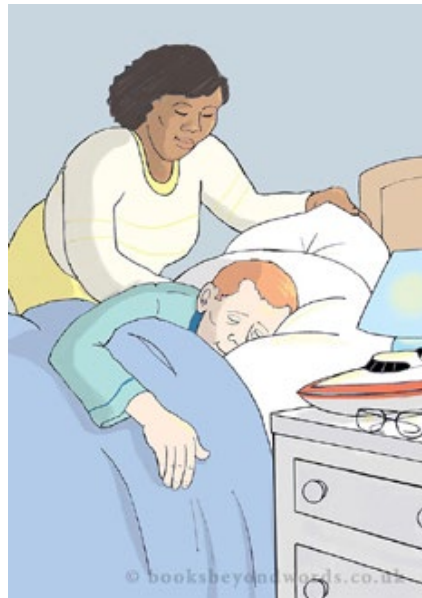
People in hospital get masks and machines to help them breathe.

Some people who go into hospital with coronavirus get better. Some people die in hospital.



If you stay at home, Gloria will look after you. Thomas won't be allowed to come close (because of coronavirus) but you can see him over there/ through the door/window. Your mum and brother can't visit, because of coronavirus. You can talk to them on the phone.

Some people who are ill with coronavirus at home get better. Some people die at home.

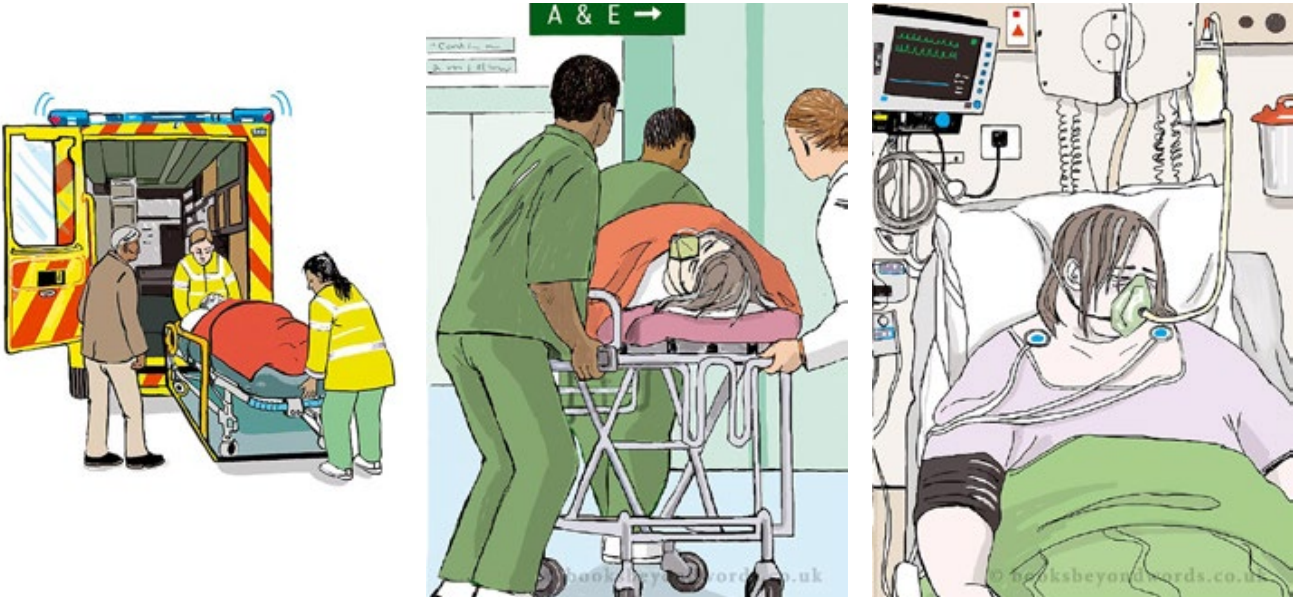


If you think that it is too difficult for Jack to cope with “what if” conversations, you could find out his thoughts through storytelling, using pictures. You could give the example of “Katie” who goes into hospital, and ask Jack whether he thinks it’s a good idea for Katie to go into hospital.



Getting ready to go into hospital

The decision to go into hospital might be quite sudden, without much time to prepare. You could prepare a “hospital bag” for Jack (and indeed for Thomas), even when they are not ill.



Here are the essential things to take to hospital

Items that are still in use (so they can't go into the bag yet) could be replaced with a note: Remember to take...

- Basic toiletries: toothbrush and toothpaste, comb
- A set of pyjamas or easy-to-wear clothes
- Jack's medication and a list of what medication he usually takes
- Phone and charger (labelled). Upload his phone with some photos and short videos of Jack when he is well, enjoying life (this will help hospital staff to see him as the person he is). You could also include any other photos that will comfort Jack when he is on his own (family, friends, support worker, familiar places, familiar items, etc).
- His glasses, hearing aid, etc (labelled)
- Favourite, familiar or comforting item
- A one-page profile (*see next section*).

“If I am ill with coronavirus...”: My One-Page Profile

This document is crucial. Without family or supporters who can be advocates, hospital staff will need help and information in order to care for people in the best possible way. What do the hospital staff need to know?

The document should be one, or definitely no more than two sides of A4 (ideally, if you can organise it, laminated), and include:

- Basic details about Jack, who he is, what he likes (with photos, ideally photos that show him living a full and valuable life)
- Key people the person wants to be in contact with, and their contact details: his mum, his brother, Gloria and Thomas), and the best way to be in contact with them (e.g. FaceTime, phone call on speaker, etc)
- The best way to communicate with Jack
- Anything that will help Jack cope with being very ill, or dying, in hospital away from his family, friends and support workers (key routines, likes/dislikes, do's and don'ts)
- Some hospitals allow one visitor for people who are dying. Check with your local hospital. If this is possible, include information about who that should be. You may need to discuss this with others, including Jack himself (for example, would he rather have Gloria with him, who is a familiar and reassuring daily care giver, or his brother?). Remember that this person will have to cope with considerable strain on their own, and that it should not be someone in an at-risk group (such as his elderly mother).

Preparing the document with Jack

You can prepare the document in advance. Ideally, with Jack when he is still well and with the help of his family, key workers, friends. Gloria could be a useful role-model by preparing such a document for herself at the same time. This helps to create a sense of all of us being in this together. It will help Jack to see we are all thinking ahead. (And hopefully Gloria will never need it, but it might come in useful for her, too.)

Here are some suggestions for how to explain it.

If you were very ill in hospital...

- *Who would you want to talk to on your phone/on Skype? (Choose a couple of people: mum, brother, Gloria). Let's write their names and phone numbers down, so the nurses will have it. They can help you to call your mum. (You might add photos)*
- *If you could only take one thing with you to hospital, what would it be? What else would you want to take with you?*
- *What can the nurses do to make you happier /more relaxed / less frightened in hospital?*
- *If the hospital would let you have one visitor, who would you want it to be? If you were very very ill, who do you want to sit at your bedside?*

Jack's One-Page Profile

Jack Jones *born 16 September 1963*



Important people:

Gloria Gaynor (carer)
tel. xxxxxxxx



Betty Jones (mother)
Doug Jones (brother)
tel. xxxxxxxx



Jack wants to keep in contact with them: he has his own mobile phone and uses WhatsApp (audio and video but not text).

Jack communicates best by: using simple words and pictures. Choose some from the BW Story App. Speak slowly, clearly and calmly. Give him time to respond. Jack can't read.

Jack is an autistic man who also has a learning disability.

Jack needs the following reasonable adjustments to be made: Jack is terrified of needles. Give him medication in other formats, or use mild sedation.

Things that make Jack anxious: Sudden loud noises; things happening unexpectedly (please explain to him what will happen next)

Things that help Jack feel relaxed: Pop music (especially Abba); leafing through his magazines (he has them with him).

If it is possible to have one visitor: Gloria Gaynor who supports him most days

Underlying health problems: Epilepsy (seizure-free for several years)

Regular medication:

Dietary needs: Doesn't like tea or coffee.

Related Beyond Words resources to help think about planning for coronavirus

Going into Hospital (2015, 2nd edition) by Sheila Hollins, Angie Avis and Samantha Cheverton, with Jim Blair, illustrated by Denise Redmond. This book helps to prepare and support people being admitted to hospital, by explaining what happens, covering planned admission and accident and emergency.

Ginger is a Hero (2015) by Beth Webb. Mary and her neighbour Mrs Hill don't get on. Mrs Hill gets really cross when her cat, Ginger, makes friends with Mary. But when Mrs Hill collapses at home, it's down to Mary and Ginger to save her life.

Beating the Virus (2020) illustrated by Lucy Bergonzi. A short wordless story, that will help people to understand what to do if you have Coronavirus and how to keep yourself and those who you care about safe. The story also shows how to safely help others who may be self-isolating.

Am I Going to Die? (2009) by Sheila Hollins and Irene Tuffrey-Wijne, illustrated by Lisa Kopper. This story deals honestly and movingly with the physical and emotional aspects of dying.

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