

Are people with learning disabilities being supported during coronavirus pandemic?

April 9 2020, by Irene Tuffrey-Wijne



Leading learning disability and palliative care expert at Kingston University and St George's, University of London Professor Irene Tuffrey-Wijne has produced illustrative materials to support those most vulnerable during the coronavirus pandemic. Credit: Kingston University, London

Leading learning disability and palliative care expert at Kingston University and St George's, University of London Professor Irene Tuffrey-Wijne, who recently [became the world's first researcher](#) to

conduct studies into palliative care for people with learning disabilities, shares her views on how the coronavirus pandemic is affecting the elderly and most vulnerable – and how she has produced two illustrative books to help those most in need feel supported at this difficult time.

If someone who normally needs high levels of support with health or social care gets ill with coronavirus (Covid-19), should they go into [hospital](#)? Should they receive intensive care? There has been widespread debate around these key questions during the past few weeks, which have been further placed in the spotlight following reports of care homes where all residents were asked by their GP to sign "Do Not Resuscitate" forms in light of the pandemic.

The issue is not straightforward. Most elderly nursing home residents are unlikely to benefit from resuscitation, and may well prefer to be spared the distress of going into hospital without being able to see familiar faces or loved ones, and dying alone, amid machinery. But these are decisions that need sensitive discussion.

Blanket "Do Not Resuscitate" decisions for care [home residents](#) have caused considerable concern—for very good reason. I have heard of homes for people with learning disabilities where GPs have told managers that all residents, who were mostly fit and well and of working age, were categorised as not requiring resuscitation during the pandemic. This was without individualised best-interest meetings or consultation with families.

Clearly, decisions about whether or not someone is referred to intensive care should depend solely on an assessment of how likely they are to recover from coronavirus and it cannot be a blanket assessment for groups of people, but must be done on an individual case-by-case basis.

Along with very many others, I have signed a letter by Disability Rights

UK to express our concern. The letter states that "where we have existing [health conditions](#) or impairments that are unrelated to our chance of benefiting from treatment, they must not play any part in decision-making regarding our equal right to access such treatment." It goes on to say that "the fact that we might have significant levels of [social care](#) and support needs, or that we may do so in future as a result of the pandemic, should not make health staff think that we will not benefit from treatment."

More than any other group of potential coronavirus patients, people with learning disabilities need others to speak up for them and help them communicate their needs and wishes. Thank goodness that many have done so, leading to the National Institute for health and Care Excellence (NICE) [updating its guidance](#) for hospital staff on deciding whether to refer patients to critical care. This now includes a statement that for people with learning disabilities, their condition should be assessed on an individual basis, without using a generalised score for frailty and dependency.

Having established that hugely important principle, how do we then make the decision whether or not someone with learning disabilities should go into hospital when they get ill with coronavirus? For many people with learning disabilities, hospital and indeed intensive care treatment is entirely appropriate. For others, being in hospital, and especially in [intensive care](#), without familiar people to support them would be utterly terrifying. It may be better for some people to stay at home and be cared for by someone they know, especially if they have underlying health conditions—something many people with learning disabilities do have—or are elderly or frail.

I have worked with [Books Beyond Words](#), a charity that produces books and training to support people who find pictures easier to understand than words. I, along with Baroness Sheila Hollins, have produced several

new, illustrated resources to guide families and carers in these difficult times—they are free to download. This includes "[Jack Plans Ahead For Coronavirus](#)," which talks about the things to consider when deciding whether someone with learning disabilities should go into hospital and suggestions for how to talk about this with them. Another resource, [When someone dies from coronavirus: a guide for families and carers](#), gives guidance on supporting people with learning [disabilities](#) when a loved one dies during this time of social isolation. We are currently working on translating these resources into other languages, and would like to hear from anyone interested in helping with this.

Provided by Kingston University, London

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