

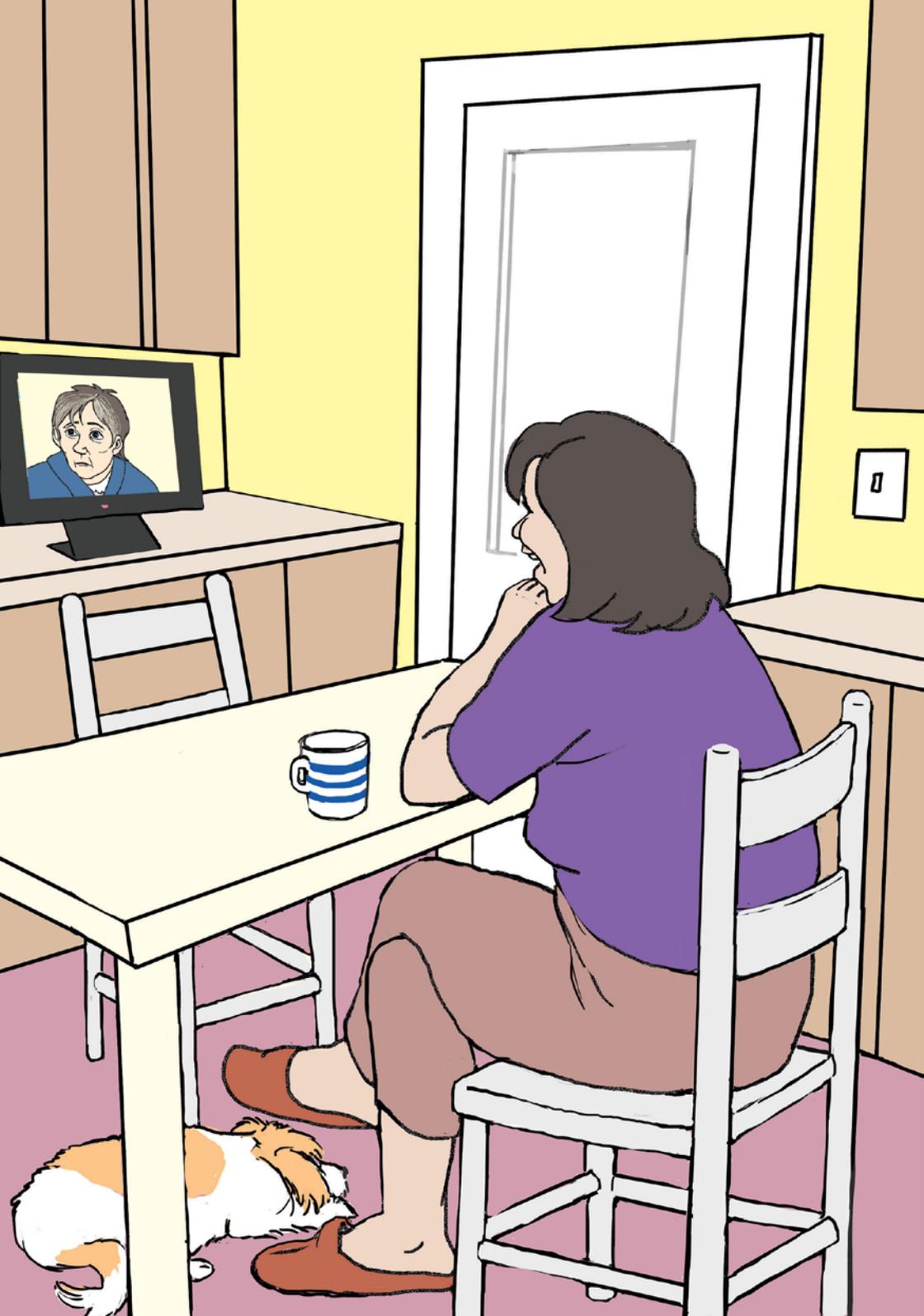
Let's talk about... when someone is ill or dies from coronavirus

Online support for people with learning disabilities

Sheila Hollins, Irene Tuffrey-Wijne and Jo Giles

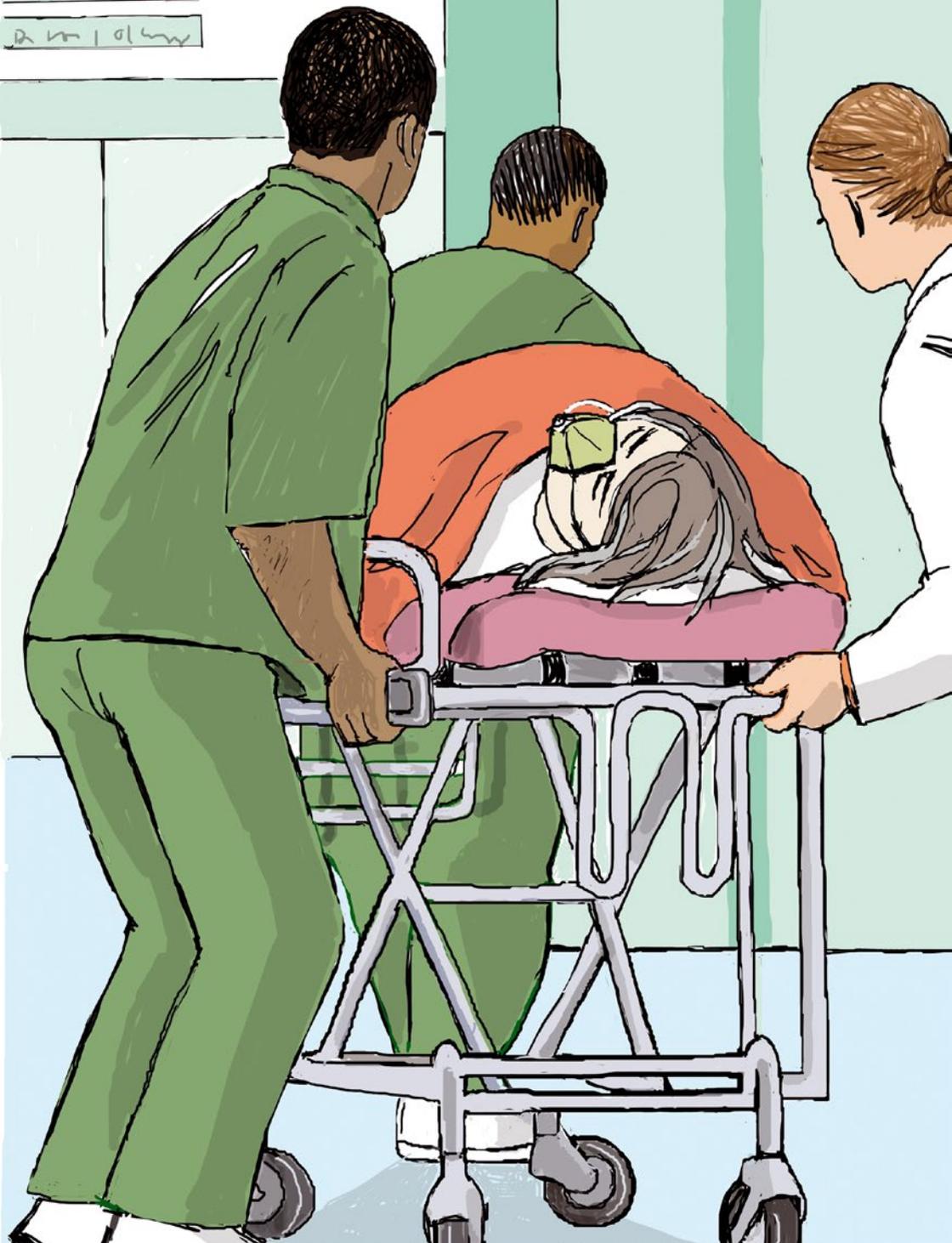


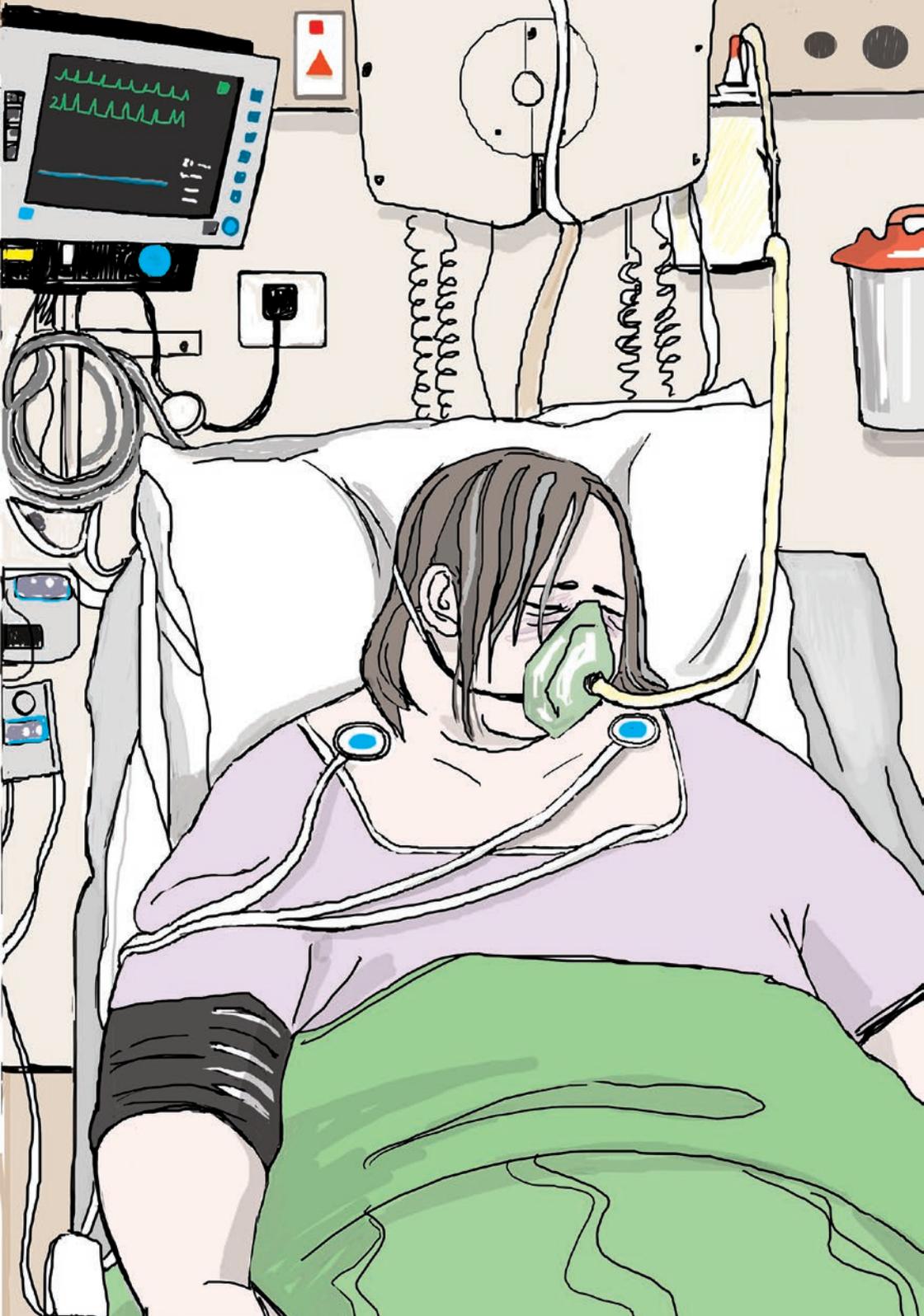




A & E →

Continuum
Dr. M. J. O'Connell



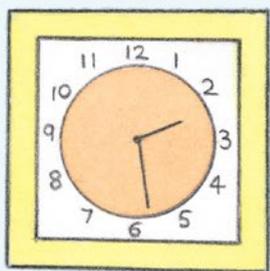














Let's talk about...when someone is ill or dies from coronavirus

Online support for people with learning disabilities

What is the resource?

A set of ten pictures that can be used as prompts to help people with learning disabilities talk about the impact of coronavirus on their lives, and especially the impact of people dying from coronavirus.

For each picture, we have created conversation prompts (see page 14) to do with the picture, followed by conversation prompts that help people relate the picture to their own lives.

The pictures are in PDF format. They can be used in online meetings with people with learning disabilities, for example, using Zoom or another online platform (or they can be used if you are meeting face-to-face with one person or a group).

How to run an online meeting for people with learning disabilities

Here are our top tips for running an online "*Let's talk about...*" meeting.

- **Have a group of up to six people with learning disabilities.** If the group is bigger, it becomes more difficult for everyone to speak and to see each other. You can gather groups of people who don't all know each other, but it helps if everyone in the group knows at least one other person. We suggest that meetings last about one hour.

- **Make sure there are two facilitators.** Their role is to ask questions, keep an eye on people to see who wants to speak or needs support, and sort out technical problems. Make sure everyone gets a chance to speak. It's harder to work out whose turn it is on video.
- **Allow time for technical hitches.** Make sure you have everyone's phone number so you can ring them if they have trouble logging on. If your online platform allows, it helps if you have the ability to mute people (for example, if someone has lots of background noise).
- **Starting the meeting:** Go round the group, inviting each person in turn to say their name plus something straightforward about themselves (e.g. "Tell us one thing you love doing " or "What is your favourite TV programme"), or show something to the camera (a picture, a pet, a favourite mug – anything!)
- **Introduce the session, for example:** "We are going to talk about coronavirus. We hear about coronavirus in the news. Some of us know people who have got ill with coronavirus. Some of us know people who have died of it. This is a really difficult time. It is extra hard because we can't be together, and we can't go out very much, and we can't see our families and friends. We are going to talk about that. We will look at some pictures. We will talk about how we feel. If you don't want to talk, that is also fine."
- **Screen share the pictures.** You don't have to show them all. Use the pictures that you think are most relevant to the people in the group. The main purpose is to help people to talk, so if you only show one picture and it leads to an hour-long discussion, that is fine!
- **Use prompts and questions about the pictures** (see below for suggested prompts, or you can use your own). Reassure the group that there is no wrong answer! Then, after each

picture, stop screen sharing and talk with the group, using follow-up prompts.

- **Ask people to raise their hand** if they want to say something. The facilitator can then give them space to speak.
- **Ending the meeting:** Finish the conversation 10 minutes before the end time. Go round the group again, asking everyone to say something unrelated to coronavirus and dying, for example: "Tell us one nice thing you are going to do this week."
- **After the meeting:** Later in the day, telephone each person in the group, to say how nice it was to see them and ask them how they are. Consider setting a regular day and time to meet with the same group.

How to talk about death

Talking about dying can be scary, but it is important to give people the chance to do so. It is usually best to use straightforward language and simple words: "Mum has died." Avoid using other words like 'passing' or 'gone onto a better place'. Some people will find such words confusing. Listen carefully to the words people themselves use when they talk about death.

Remember, if people get upset, it is not you who has caused the upset. It's the situation they are in! What you have done is help people to express their distress. That is important.

If someone is crying, you can help them by saying something like "We can see that you are very upset. I understand. It really is upsetting." You can ask if others in the group want to say anything to that person or whether anyone else has felt like that too.

These are important conversations to have. People with learning disabilities told us:

"It is hard. You have to be prepared for people to be upset. But it is part of life and we want to talk about it. Talking together makes you feel you're not the only one suffering this sort of thing. You're not on your own."

Conversation prompts for each picture

Here are some prompts that may help with starting conversations. There are questions about the picture and then prompts to start conversations that relate to people's lives. You can remind people that they don't have to talk about their experiences if they don't want to.



Questions about picture:

- What do you think is happening in this picture?
- Who do you think the people are in the picture?
- If they could speak what would they be saying?
- How is each person feeling?
- How does this picture make you feel?

Prompts for people to relate it to their lives:

- How are you having to stay apart from people?
- How does it make you feel?
- What are the hard parts?
- What helps you through this?
- Are there any good things about keeping apart?



Questions about picture:

- What do you think is happening in this picture?
- Where do you think the woman sitting down is?
- Who are the people in this picture?
- How do you think each person is feeling?

Prompts for people to relate it to their lives:

- How have you been speaking to or seeing people?
- How has this made you feel?



Questions about picture:

- What is going on in this picture?
- Where are these people?
- Who do you think is on the trolley?
- Why do you think the person is on the trolley?

Prompts for people to relate it to their lives:

- Do you know anyone who has been into hospital with coronavirus?
- Would you like to tell us about it?
- How did you feel about them being in hospital?



Questions about picture:

- What do you think is happening here?
- Why do you think the person has all this equipment around them?
- How do you think the person is feeling?

Prompts for people to relate it to their lives:

- How do you feel when you see someone feeling ill?
- If someone you know is ill, how could you show that you care about them?



Questions about picture:

- What has happened to the patient?
- Why do you think the nurse is putting the sheet over the woman?
- How do you think the nurse feels?

Prompts for people to relate it to their lives:

- When you see that this person has died, how does it make you feel?
- Have you known anyone who has died?
- Do you want to tell us about it?



Questions about picture:

- What is going on here?
- Who is calling who here?
- What do you think they are saying?
- How do you think the man is feeling?

Prompts for people to relate it to their lives:

- How does this make you feel?
- How would you like to be told news like this?
- Who would you like to tell you?
- Has anyone ever told you bad news on the phone?
- *(If the person knows someone who has died) How did you find out that someone had died?*



Questions about picture:

- What is happening here?
- What are they thinking about?
- How is each person feeling?

Prompts for people to relate it to their lives:

- How do you think you would feel in this situation?
- What would help you?
- How could you take care of yourself when you feel like this?

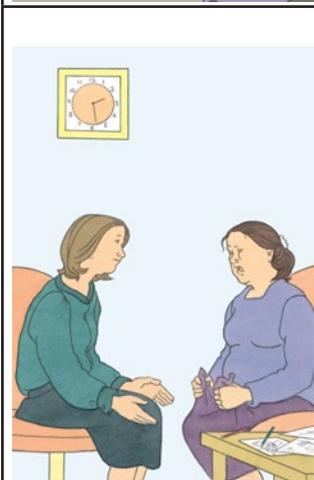


Questions about picture:

- What is happening here?
- What are the two people watching?
- Why are they watching this?
- How are these people feeling?

Prompts for people to relate it to their lives:

- What do you think you would feel if you couldn't go to the funeral?
- Has this happened to you? What was it like?



Questions about picture:

- What is going on in this picture?
- What are they talking about here?
- How do you think the woman on the right is feeling?
- What is the woman on the left doing?

Prompts for people to relate it to their lives:

- Who would you choose to speak to if you were upset about someone being ill or dying?
- Is there anything else, apart from talking, that would help you?



Questions about picture:

- What is happening here?
- Where are the two people?
- What are they doing?
- Why are they doing this?

Prompts for people to relate it to their lives:

- What else can you do to remember people after they have died?
- Is there a way that would help you?

Related Beyond Words resources

Illustrated guides for family and carers

- **Jack Plans Ahead for Coronavirus: A guide for family and carers.** A free illustrated resource on end of life care planning in the context of coronavirus.
- **When Someone Dies from Coronavirus: A guide for family and carers.** A free illustrated resource on how to respond when somebody dies from coronavirus.

Both guides are available to view online and download for free: <https://booksbeyondwords.co.uk/coping-with-coronavirus>

[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.

[When Somebody Dies](#) (2014) by Sheila Hollins, Sandra Dowling and Noëlle Blackman, illustrated by Catherine Brighton. Mary and John are both upset when someone they

love dies. They learn to feel less sad by attending regular bereavement counselling sessions and from the comfort and companionship of friends.

[When Mum Died](#) and [When Dad Died](#) (both 2014, 4th edition) by Sheila Hollins and Lester Sireling, illustrated by Beth Webb. Both books take an honest and straightforward approach to death and grief in the family.

[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.

Authors and editors

Sheila Hollins is Emeritus Professor of Psychiatry of Disability at St George's, University of London, and sits in the House of Lords. She is a past President of the Royal College of Psychiatrists and of the BMA. She is the founder, lead editor and Executive Chair of Beyond Words, and a family carer.

Irene Tuffrey-Wijne is Professor of Intellectual Disability and Palliative Care at Kingston University & St George's, University of London. She is a trained nurse with extensive clinical experience in both hospice and learning disability services. Over the past 20 years, she has done research around the end of life care needs of people with learning disabilities, with a focus on communication.

Jo Giles works on a range of projects at development and training organisation Paradigm, from The REACH Standards to The Gr8 Support Movement. Outside Paradigm, Jo is

also an End of Life Doula with Living Well Dying Well and supports Professor Irene Tuffrey-Wijne to run a group for people with a learning disability to talk about death and loss. Jo is also a Gig Buddy with Gig Buddies and was the creator of www.easyhealth.org.uk, a website designed to ensure easy read health information is available to all.

This work is licensed under the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International License. To view a copy of this license, visit <http://creativecommons.org/licenses/by-nc-sa/4.0/> or send a letter to Creative Commons, PO Box 1866, Mountain View, CA 94042, USA.