

Every picture tells a story

How the lack of available communication resources inspired psychotherapist **Baroness Sheila Hollins** to create interactive picture books to help nurses broach difficult subjects with their patients



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Books Beyond Words was set up in 1989 to create books which would empower people who have learning disabilities and struggle with the written word.

The books were inspired by Baroness Sheila Hollins's experience as a psychotherapist when she couldn't find resources to help her communicate with a non-verbal patient about his father's death.

The first titles, *When Mum Died* and *When Dad Died*, were published during the company's first year. Now there are more than 50 titles as well as a newly launched app covering themes including abuse, bereavement,

depression, going into hospital and love and relationships.

Great Ormond Street Hospital consultant nurse Jim Blair has used *Books Beyond Words* for 16 years with people who come in as outpatients for appointments or heart procedures or when they are feeling low or are admitted into hospital. He says using the books allows patients to communicate their understanding of a particular issue and what they are concerned about.

'The books build someone's own journey through health,' he says. 'Giving the person with learning disabilities a book is a powerful way of showing they



▲ Clockwise from top: Baroness Sheila Hollins with a client; colouring in during a *Beyond Words* workshop; interacting using a visual book; Mencap's Liz Mincer with author and adviser Lloyd Page

are leading the interaction and shaping where it will go.'

While Mr Blair says the level of communication varies, the ability to see pictures is essential to allow the person with a learning disability to demonstrate engagement through facial cues, verbal gestures, language and physical movement. In this way, the picture format becomes a two-way conversation, where the nurse can, for example, prepare them for blood tests and understand whether this makes them feel anxious or scared, without being distracted by the text.

'Many people with learning disabilities believe that books aren't for them,' says *Books Beyond Words* executive director Danny Curtin. 'But with a visual story, it doesn't matter about word literacy.'

He encourages nurses and other healthcare professionals to view the books as a great way to place people at the centre of their own decision making.

'As soon as you strip out words and relinquish control to the patient, it gives them confidence.'

Inform, educate and support

The ways in which the books are used by Jane Williams and therapeutic support service staff at Bryn y Neuadd Hospital in Llanfairfechan, North Wales, include:

- » Assessments of insight into diabetes.
- » Establishing degrees of mental capacity in consenting to take a medication.
- » Supporting people through the changing trajectories of health and illness in a wide range of subject areas.
- » Therapy through bereavement, difficulties with anger and getting upset, depression and poor mental health.
- » Transition through services.
- » Supporting patients' involvement in their care in an empowering way.
- » As a social context for patients' voices.
- » To talk about general health subjects in groups or one-to-one.
- » To talk about more specialist subjects in groups or one-to-one.
- » To evaluate care as part of Care Quality Commission inspections.
- » Co-designing and co-providing training to evaluate care and treatment plans in hubs in England.
- » Given training and presentations across the local health board, and other parts of the UK.



For Jane Williams, who is a learning disability nurse therapist/ interim unit manager at Bryn y Neuadd Hospital, Llanfairfechan, Caernarfonshire, Books Beyond Words resources have become an integral part of patients' care plan.

'They have become invaluable to help the staff support patients to input into their care,' she says. 'We are eliciting something which is personally meaningful to the reader. A person may be able to reframe themselves and present an empowered version of who they are now.'

♥ *The books' narrative helps to encourage shared development*



'In a group, there is a sense of connectedness with other people,' she says. 'Our book groups and one-to-one sessions are an excellent vehicle to connect with other people.'

'The shared development of a narrative can flatten the power of differences that exist between us.'

Centre stage

Ms Williams's colleague, learning disability nurse Ifan Williams makes frequent use of Books Beyond Words resources in his clinical work. 'They give everyone the opportunity to have an equal chance of being heard and taking centre stage, delivering their own personal story... for a change.'

Each book undergoes an expert-based co-production process with around 100 people with learning disabilities reading each one before the story and artwork are finalised. One person with a learning disability

How to read Books Beyond Words

There is no right or wrong way to read a Books Beyond Words title. Remember it is not necessary to be able to read the words.

Some people are not used to reading books. Encourage the reader to hold the book themselves, to turn the pages at their own pace, and to read the story they see in each picture.

Whether you are reading the book with one person or with a group, encourage people to tell the story in their own words. You will discover what each person thinks is happening, what they already know, and how they feel. You may think something different is happening in the pictures yourself, but that does not matter. Wait to see if their ideas change as the story develops. Do not challenge the reader(s) or suggest their ideas are wrong.

Some pictures may be more difficult to understand. It can help to prompt the people you are supporting, for example by asking:

- » Who do you think that is?
- » What is happening?
- » What is he or she doing now?
- » How is he or she feeling?
- » Do you feel like that? Has it happened to you/your friend/your family?

You do not have to read the entire book in one sitting. Allow people enough time to follow the pictures at their own pace. Some people will not be able to follow the story, but they may be able to understand some of the pictures. Stay a little longer with the pictures that interest them.

who was involved in the process said: 'They really involved us in talking about the books. They say: "Nothing about us without us" – I find that Books Beyond Words is part of that.'

Mr Curtin stresses the importance of the resources in their role in health promotion. Research into the benefits of a leaflet about testicular cancer – How to Look After my Balls – found that a group of men who had the leaflet had greater knowledge about self-checking after six months in comparison to those who did not have access to it. As Mr Curtin argues, 'We're levelling the playing field with regard to healthcare.'

This year, Books Beyond Words will publish two books about belonging in the community and a church community, and in 2018 there will be a series on the subject of work.

Resources

The Books Beyond Words app is a convenient way to access the stories at <https://itunes.apple.com/us/developer/books-beyond-words/id1086463127>

The leaflet *How to Look After my Balls* is available online at tinyurl.com/zg9ukbv

Guidance on how to use Books Beyond Words resources is available at booksbeyondwords.co.uk