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# Developing a resource to help parents explain cancer to their children

Parents who have cancer may struggle to talk to their young children about their illness, and also to find suitable resources to help. Most existing resources, particularly story books, use heteronormative images that do not reflect the diversity of modern families, and many are disease specific, rather than discussing cancer in general.

## How it all started

As a supportive care lead nurse in a cancer centre, I was aware of the paucity of resources to help newly diagnosed patients talk to their children. In 2014, I had the idea to write a series of children's books to encourage and support people with cancer to talk to their children about their condition and treatment.

Along with my equality and diversity manager, I decided to produce books that would not only be evidence based but also reflect the diversity of modern families. I also wanted to ensure they would be available in British Sign Language (via YouTube), in audio versions and in Welsh.

We held meetings with key internal and external stakeholders (clinical psychology, social work, education, Diverse Cymru, Marie Curie and Barnardos) and presented a paper to the executive board of Velindre Cancer Centre to tell board members about the project and gain their support.

## Developing the resource

A nine-year-old boy attending a local bereavement group came up with *Caring for my Family with Cancer* as the generic title for the series of books. Using patient stories, modern technology and computer graphics, the first book was successfully launched in 2015. It was designed so it could be easily altered to feature different family configurations – single-parent families, same-sex families, families in which the

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children are raised by their grandparents, and so on.

Cardiff-born actor Matthew Rhys, a patron of fundraising at our cancer centre, provided audio versions of the book – one in English and one in Welsh, which he professionally recorded in a studio in Los Angeles. The audio versions and the BSL version were launched in 2016 during Sensory Awareness Week.

The book features two lions, one large and one small, which are used as a strategy to deal with separation anxiety. When one of our patients and her husband heard about the book, they offered to donate 5,000 cuddly toy lions to accompany it.

We developed a practical guidance tool for parents to use before they tell the story to their children, and a training session to explain the resource to cancer nurses.

## Feedback from families

From May 2015 until May 2016, 68 copies of the first book were given to families and we listened to their feedback, as well as to what key stakeholders and professionals had to say. The feedback from families was extremely positive. Comments included:

*“Our daughter is only little but the book really helped her to understand the difference that Daddy has cancer and not just a ‘baddy’ leg. It helped us, as parents, find the right words to explain it to her.”*

*“The book is such a fantastic idea. It is so clear, colourful and easy to follow.”*

*Our boys also loved the cuddly lions. It gave us confidence to talk to them about this.”*

After the book's launch, two boys attending the children's bereavement group after their mother's death brought their memory boxes – nestled in one was the cuddly lion given to them by their mother when she had used the book with them a few months earlier. This demonstrated to us the importance of the resource in supporting families, not just at the time of diagnosis or treatment but also into bereavement, by helping to provide positive memories.

## Future plans

The cost of the project has been approximately £10,000, which includes printing, digital illustration, and BSL and Welsh translation fees. The money was raised by our fundraising department and agreed by the executive board. We often worked in our own time to keep the project on schedule.

We now have six versions of the book – with a mother with cancer, a father with cancer, single parents and same-sex parents. We are planning to launch a book for grandparents in 2017. The series will continue to grow as needs are identified.

The books – and accompanying lions – are given to our patients and their families for free. They are not currently for sale, but we are working with our fundraising team on how we can share them with other organisations to help support more families. **NT**