



MacIntyre

Providing support...your way

Dying to Talk Case Study

Introduction

Janet is 73 and lives in Leicestershire. She has had five pregnancies and has three children, Brendan who is 53 and lives in Shared Lives, Ellie who is 47 and lives in a MacIntyre Residential Care Service, and Claire, who died in 2015 in her 40s. Janet has been widowed twice.

Janet was interviewed for this case study.



Background

Brendan, Ellie and Claire were all born with Smith-Lemli-Opitz Syndrome, a rare genetic condition affecting multiple body systems that was diagnosed at Great Ormond Street Hospital. Brendan was five when he was diagnosed, Ellie and Claire were younger.

Janet says:

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No one believed me when I said my children weren't developing normally. When Brendan was finally diagnosed, I was told; 'He'll never walk with steadiness, never talk, never have gross or fine motor skills, but don't worry, they can be very loving.' I thought; 'Yes he will walk. Yes he will talk.' I concentrated on the social side of their development to give them the best preparation for adulthood. I fought for everything. They went on to become very sociable, outgoing, funny, happy, lovely, beautiful children who made friends easily.

When Claire was 22 and Brendan was 24, Claire expressed a desire to live independently. Brendan felt likewise, and eventually Claire found a place in Supported Living, Brendan went into Residential Care, and Ellie - who can walk and feed herself but doesn't talk and is the most profoundly disabled sibling - moved into a MacIntyre Residential Care service.

More upheaval followed when Brendan's care home with another provider closed down. Brendan moved into a bigger flat with Claire and they had extensive support. However, the biggest blow to the family came when Claire developed a brain tumour.

Janet says of this time:

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Claire coped so well with the diagnosis, she was so stoic and brave, even though it came at a time when was in a dark place.

Janet continues:

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I needed to find emotional support for Claire, so I arranged for her to go to a local church. She loved it. Brendan and I eventually went to the church too and Janet and Brendan were baptised.

Claire developed a strong faith and started to say to me: 'Am I dying?' I would shrug it off, but eventually she got very poorly and went into a hospice for two weeks. The hospice said Claire could stay longer and she ended up being there for three months. She kept asking 'Am I dying?' Eventually I said: 'I think Jesus might be calling you home.'

It was the hardest conversation I've ever had to have, but I felt Claire had a right to know. Claire cried. I said: 'Everything will be ok,' to which Claire replied, 'Yes, but what about you?' She was so concerned for me, Brendan and Ellie.

Janet told Brendan that Claire wasn't going to get better, and she has some beautiful photos of Brendan with Claire in the hospice.

Explaining that Claire was approaching the end of her life was more difficult with Ellie.

Janet explains:

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It's very difficult to know what Ellie understands. I go on the assumption she is taking things in. We told Ellie, her staff told her too, and Ellie visited Claire.

Janet vividly remembers Claire's death:

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It was Brendan's birthday on the 4th of August. He and Claire were born two years and a day apart. Claire's birthday was on the 5th of August and she died on the 6th. She was happy and peaceful in my arms. I believe that Claire's faith got her through her terminal illness.

Janet delivered a eulogy at Claire's funeral and when she'd finished Brendan wanted to speak too.

Janet says:

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It was remarkable that he could stand up in front of a full church and speak. He told everyone: 'She was my sister and I loved her so much.'

Ellie came to Claire's funeral too, as did many of the hospice staff.

Brendan subsequently moved into Shared Lives where he is happy and well-adjusted. Ellie is still in a MacIntyre Residential Care service and her staff take her to church regularly. Janet thinks Ellie enjoys this, although as Ellie is non-verbal her responses are from her body language.

What we have done

Listened to Janet

Creating this case study has been primarily about listening to Janet's experiences. She has been very candid and honest about being a parent to children with learning disabilities, and how she has coped with grief and bereavement. She is the most amazing cheerleader for her children and a very positive and inspirational person.

Janet sums up her experiences as a mother as follows:

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I've learnt to live for the day and do the best I can. As a mother you try to meet your children's needs to the best of your ability no matter how old they are. My children are different, but they've achieved so much and overcome so many difficulties.

Supported Janet through a Dying to Talk workshop

Janet attended one of the Dying to Talk Project workshops in March 2022, led by Irene Tuffrey-Wijne, Dying to Talk Project consultant.

Janet explains:

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I was asked by Jess from MacIntyre if I'd be prepared to come to the workshop. I was happy to attend and to share the experiences I had with Claire. It was a brilliant workshop and we had a great time. Irene made everything we did fun, despite the sensitive topic.

Provided resources

During Janet's interview for this case study, she asked for some resources that focus on planning for the future and end of life care, and we were happy to provide the pack of resources that we developed during the Dying to Talk project.

What did we learn

Janet has found her own ways to cope with Claire's death and being widowed twice. Janet says of this experience:

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Death is part of life. I've done my crying over the years, but privately, not in-front of my children unless we've been crying together. We have to find ways to cope – it's got to be done like anything else. I have to carry on for Brendan and Ellie.

Knowing about and supporting people's faith preferences is crucial: faith has played an important part in the lives of Janet, Brendan and Claire.

Janet says:

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Brendan and I talk about Jesus dying for us. His Shared Lives family are a Christian family and that is very important for him. It's important to me too that his faith is supported.

How we can support families with planning for the future

Janet has shared ideas with us about what she thinks would help families to have conversations about death and dying.

Janet says:

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Support needs to be really inclusive, with children, parents and staff all together. For Brendan, it means myself and his Shared Lives family working together. I would also love to see more films or books on this topic too.

What are we pleased about

Janet's openness and willingness to share: Janet says of the bereavements in her life:

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I've always been open about everything. The children's first experience of bereavement was their grandparents, and I started talking to them about bereavement then. Then my second husband died, and then their dad. And pets too.

Janet continues:

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A lot of parents shield their children from death and dying. They think it's beyond their ability to understand. We all have to learn – we can't expect to know about something if we don't learn about it. It's a massive fear for many, many parents, and I understand that. I've often wondered, if I'd died before Claire, how would she have coped? It's very sad it was the wrong way around but in some ways I'm glad it was.

What are we concerned about

The barriers for families around making future plans. We know from all of our Dying to Talk Project work that families find conversations about the future and planning for their (adult) child or sibling's end of life care very challenging. This is something we know we need to continue to provide help and support with.

Janet says:

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I haven't done any planning for Brendan and Ellie. With Ellie I wouldn't know how to approach it. With Brendan, if it came up I would discuss it. If he wanted to talk about it I would. But it's a difficult topic, because although we've been through Claire's death and Brendan will talk about Claire, sometimes doesn't want to.

What next?

Continuing to work with MacIntyre families. Although the Dying to Talk Project has ended, we continue to work with families across MacIntyre.

Janet says:

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I really hope that this case study helps other parents and carers. We all go through sad times, but we can cope by looking back on the happier days and holding onto our memories.

We are so grateful to Janet for working with us to develop and publish this case study.