Kevin’s story

Context

This is a story told by Kevin, whose partner Ella died from cancer in 2010, only four months after receiving a diagnosis of terminal melanoma. Kevin was a mental health youth worker at the time. The couple had a twelve-year-old child Carrie and here, Kevin talks about the challenges and complexities of his caring role. He reflects on what helped and hindered him on this journey and hopes that sharing his story might help other unpaid carers, professionals and indeed, people who find themselves in both roles.

Diagnosis and prognosis = worst fears realised

My story starts at the Beatson oncology centre with my partner Ella’s cancer test results at the end of July. That was such a difficult day. The consultant broke the news that Ella’s was a very aggressive form of melanoma and palliative care was the only option. Our worst fears came true.

Before we got the diagnosis, I spent weeks on the internet. At that point in the journey I wish I’d had access to simple and clear information about what to expect. Left to my own devices I was trawling the net, finding overly jargonised medical information which made me feel hopeless. I wish someone could have told me where to get good information.

Waiting for diagnosis and prognosis is a dreadful period of anxiety. I can honestly say I have never felt anything nearly as painful as that. For me, the diagnosis is the most critical part of the system of care. You are confronted with a big bureaucratic system, and it’s easy to get lost in it. We would turn up for tests at the Royal, would end up in Stobhill and then on to Clydebank. Three hospitals for one test and then weeks for the results.

Family dynamics and breaking the bad news to a child

Bearing in mind I’ve got a young child, the reality of thinking I’ve got to care for wee Carrie on my own kicks in. You’ve got so many dynamics there, the physical care, facing the loss of my partner, the care of my daughter on my own and then knowing that Ella’s role as a mother was coming to an end and that Carrie was losing her mother. They were many causes of emotional distress and I had to work out how to cope with all of that to manage the caring.

It’s always a dilemma about when to tell a child bad news. We were clear that we would tell Carrie but there was an issue of who, when and how. Ella didn’t want to be the one to tell Carrie so it was my role. I can remember as clearly as if it was yesterday. I had to tell Carrie that her mum was very ill and she wasn’t going to get better. Part of that conversation was about reassuring Carrie that I could care for her. Carrie was confused, dazed and upset. How she coped was incredible really.
Carrie understood that her mum needed her to be ok and we did try to do nice things together. Carrie brought a lot of comfort to her mum. She cheered her up just by being there, telling her about her day at school, taking her homework to hospital. I was so exhausted sometimes that it was a relief to be able to sit back and let Carrie do the chatting. She supported me emotionally and would give her dad a hug. I think treating her as part of the team was the right thing to do.

From partner to carer and the importance of professional support

In Ella’s head there was some denial about this cancer that was going to kill her. At the start she couldn’t cope with the mismatch between how well she felt and the reality of her body deteriorating. I started to telescope the caring role too quickly. I used to say to her ‘slow down, don’t go to your work’ and Ella’s retort would be ‘I’m not dead yet, shut up.’ Quite rightly she would tell me to back off, and that I was still her partner. It was good for me to get coached by Ella.

I come from a nursing background. Although I had professional experience of cancer care, when it came to me being in that situation, like anybody else, I panicked. The nurses who visited our home from the Royal Infirmary played a crucial role in emotionally supporting us. They had a conversation with Ella about how to talk to me and about the different relationship we would have. I know Ella was relieved after that because she had a language she could talk to me in where we could negotiate my role, including intimate care.

One day a nurse produced this red box with all the medicines it. She taught me what the medicines were for, their effects and how they could be used. Having it all explained was reassuring to me so that both Ella and I could trust my knowledge, ability to care and to manage her pain effectively.

Loss, loneliness and points of connection

It can be a cold process, losing your partner. You feel estranged from the relationship you were in because you are watching a dying person. It might be different now and I hope it is, but my experience of being a carer in the hospital setting was lonely. It would have been traumatic anyway, but the lack of connection didn’t help.

I think it can be difficult for professionals to know when to talk to carers. From my experience, you wouldn’t want every professional talking about death. But then there are times
when you really need someone to talk to. I don’t remember anyone pulling me aside during the lonely hours when Ella was going through chemotherapy and was out of reach from me. I’m sitting there for hours or days on my own. The nurses at the Beatson were nice and the physical care was brilliant, but many times I felt lonely.

One of my best experiences at the Beatson was bumping into my friend Andy Barr, who works in palliative care. That was the best conversation I had. He gave me a hug when I told him about Ella and he took me for a cup of tea. He was very kind. For him to make me feel normal was just so helpful. Don’t get me wrong, Ella had really good relationships with staff in there. But I didn’t have that.

I didn’t take up official counselling because I didn’t have the time. Twice I took the offer of a lift to get a massage. The driver was a volunteer whose wife had died of a cancer a year earlier. He talked about how he wanted to avoid others feeling as lonely and desperate as he did. I thought that was amazing. The conversation in the car was a hundred times more important than the massage. The second time he gave me a wonderful poem about how to remember a person after they pass away. I included it in Ella’s commemoration.

Being a carer can also be as lonely as you let it be. One thing I learned from being a professional nurse and previous life situations was the importance of letting other people help. So Ella’s friend April got alongside me and we spent a lot of time together. We talked about what Ella needed and looking after Carrie. I had to find a way of caring that included the other person Ella trusted most.

Moving to the hospice and a different caring role

Although Ella had limited awareness by then, the hospice transformed our experience as a family. Even though the end was close, we were less distressed in some ways. There was some relief that Ella was going to get quality care and I was fulfilling our agreed plan. And because I was slightly stronger myself that meant things were better for Carrie and for Ella’s family. When Ella was admitted, the manager pulled me in for an hour and held my hands. I was struck by how different it was. I feel emotional thinking about it. Sometimes I think professional boundaries get in the way of good care.

For the first two days Ella was still able to make decisions, including about who could visit and so on. There were things I wasn’t to speak to the nurses about. She was still caring for me and didn’t want me to know how bad things were. That is such a sweet thing to do. That’s one of the last times I saw her point her finger at me, telling me not to ask the nurses for information. I had to respect that even though as a nurse I wanted to know more.

I made my nursing background known and they talked to me
about resuscitation, about end of life care, fluid intake. It was good to be able to share that with Ella’s family. I was able to be the mediator for the whole group. It made me feel that I was doing as much as I could do for Ella and the family, and it also took the pressure off staff.

There was a social worker in the hospice dealing with the money side, which I just couldn’t have dealt with by then. We were down to one income and Ella was the only driver in our house. The social worker completed the DLA forms, which meant there was payment for me to get taxis to see Ella, and I could keep paying the bills. That practical support and advice was a lifeline at that stage.

**After Ella**

The caring journey didn’t stop when Ella died. The first thing you have to do is make sure that the memory of the person who has died is respected. You are very conscious that you want the family to know that the funeral is well managed. That is a time when professionals could offer emotional support, because you feel lost and empty, and a chat might encourage you to seek support if you struggle at this time.

Macmillan and Marie Curie both offered me a lifeline and it was important to know that was there if I needed it.

Then there is the changing parenting role. You are committing to your child’s future as a single parent and seeking motivation to keep going. I had to speak to Carrie’s GP about potential counselling, her guidance teacher and every couple of months would check with the teacher about how she was doing. I was offered reassurance that the school were keeping an eye on her. It was as key part of the scaffolding. There is a safety net there when one parent dies because you need to know that there is a source of support for your child to help to maintain them, and you.

Other parts of the community played a role too. Carrie had continuity through going to the scouts. That gave her routine and a different set of friendships on a Tuesday and Saturday. It also gave me a break, and other parents were checking in with me to make sure we were both ok. The dance class played a similar role. There is something very comforting about feeling connected and having normality which can really help with loss.

My friend Colm arrived back from working abroad one week
before Ella died and he played a key part in supporting me and Carrie for the next four years. It was a new structure, a new set of roles and a new chapter. I had by that time come to accept that I had to let others in to offer help and support. That was partly triggered by the volunteer driver from Macmillan. He prepared me for that. Colm supported me emotionally too and gave me breathing space to work, to grieve and recover. I could not have kept my job going otherwise and we would have been impoverished.

I mentioned Ella’s friend April already and she was important at this time too. We bonded through sharing the same sense of loss. She was in pain too and there was something about our shared memories and that was important to each of us and also to Carrie for moving on. You don’t want to lose the relationships important to the person who has gone because you want that continuity.

Reflections on being an unpaid carer and a caring professional

There are contradictory effects of being a caring professional in a family caring situation. Although as professionals we might have useful knowledge that can help us in our caring roles we need to accept that a caring background does not make us immune to needing help and advice as a family carer. Because we have experience of working in the system I think we also see things differently at times. It throws it all into sharp focus. You can get agitated because you have expectations of how things should happen but you also hugely appreciate it when you get that human connection.

It’s good to know that there is a new Carers Act in Scotland. This could be a big step forward, with opportunities to involve carers more from an early stage. This can only benefit the person being cared for, the main carer and often many other people involved as well as staff. In my case I wasn’t aware that carers could be assessed and this was never mentioned. Looking back, this could have been really helpful at an early stage and I would have particularly valued:

- **feeling better informed** about melanoma, especially at the diagnosis stage
- **being able to access advice** on adapting to rapidly changing family dynamics and doing the right thing for my child
- **emotional support from an identified professional** who I could seek out at critical points, to help cope with feeling overwhelmed by loss and the complexities of caring
- **financial advice at an early stage** to avoid anxiety about not being able to make ends meet and to be able to continue caring effectively by visiting my partner in the hospice and looking after my child
- **understanding and thinking through the importance of being connected to diverse community resources** including family and friends, services like the school and the GP, and informal resources like the scouts and dance
Actually telling my story and being given a chance to shape it with you has been cathartic. These intense life and death experiences can feel so fragmented. Telling this story feels an important part of my long-term recovery and it feels like it has kind of cohered in a new way. Being able to own the experience and make deeper sense of it is helpful. It feels clearer. And actually I think I did all right during that. I think I did well. A lot of people find it hard to recover from loss and I can understand why. I’ve been lucky to have the support I’ve had over the years. And the support from staff at the time, when I got it, was invaluable.

I have worked in the care system my whole life and I know how difficult it can be to maintain your values and your compassion. There are so many competing pressures. But being on the other side of it, as a carer, has been a powerful reminder to me about how important it is that you show that you care and understand and that you leave a bit of hope. I know that everyone’s story is different and we all need different things but I think it’s universally the case that it’s amazing what difference a few kind words can make.

'Kevin's story' is an extract from the eBook *Personal Outcomes Planning Resource* published by the Scottish Social Services Council. You can find a link to download a copy of the eBook and other resources relating personal outcomes at [learn.sssc.uk.com/popr](http://learn.sssc.uk.com/popr)