

One woman and her dog

Kathy Moore
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Kathy Moore and her dog Do-Good work for Seesaw, a child bereavement charity based in Oxford, UK. She is one of the first specialist pre-bereavement support workers for children and young people in the UK, initially funded by Macmillan Cancer Support. Here she talks about her work, and Do-Good's special role in supporting children and young people facing the death of a parent.

Seesaw was set up in 2000 in Oxfordshire to support children when a parent or sibling has died or is dying. Part of the service we offer is a specialist worker to support children before the death. I was appointed to the post about six and a half years ago. I'm a social worker by background and before joining Seesaw I worked for Clic Sargent – previously called Sargent Cancer Care for Children – at the John Radcliffe Hospital in Oxford, supporting children and their families in the oncology unit.

The work with children at Seesaw is very different – supporting families where one of the parents is dying has a completely different focus from working with families where the child is dying – and it took me a while to adjust. In the one you're focused on a child's life ending, and in the other it is the child's life that is continuing – the support needs of the parents and the children are totally different.

Referrals tend to come from professionals such as Macmillan nurses, doctors and health visitors, who have contact with the family and suggest they might find it helpful to get in touch with me. I don't contact families unless they have expressly said they are interested in seeing me. I have between 15 and 20 families on my caseload and I work with children up to the age of 18.

My role is all about helping families communicate. My aim is to help the adults think about how children think, and give them the tools to manage the situation themselves. It's no good if the children feel they can only talk to me – that's not going to help them when they are older or when I'm not around.

With referrals for younger children, I will make an appointment to meet the parents first, to introduce myself and find out what their understanding is of

the prognosis and what they have told the child(ren). Sometimes that initial conversation will be enough and we'll decide that, although in the long term prognosis is poor, things are going quite well at the moment and it feels too soon for my involvement.

If that isn't the case, I explain my role and how I work. I make it very clear that I'm there to support them as a family, and that, when I get to know the child or children, we will always talk to the parents about any questions that the child(ren) may have. I'm also very clear that I'm not a counsellor. I give them my contact details and tell them to get in touch when they have decided they want me to meet the children. If they say yes straight away, I'll make another appointment there and then.

The earlier I am in touch with the family the better, even if I don't then work with them straight away. I've found that this allows time for us to build up a relationship, so that when things change, the family already know who I am and how to make best use of my support.



Telling young children

Often the adults won't have told the children and it is part of my role to help them think about how they are going to tell them, and when. I won't tell the children myself. Even if the parents have told the children, the children may not have understood. I need to find out what the children understand from what they have been told – it often isn't the same thing.

I try to help the parents take their 'adult hat' off and think how a child thinks. With younger children, you can only tell them what you know, and it's important that this links with what they can see. They have a different sense of time. We adults forget that children tend to live in the present moment and only really take on board what is happening in the here-and-now; they don't project forward in the way that adults do. It means nothing to a younger child to be told that Mummy has three months to live. That notion of time is hard for them to comprehend. If a young child is told their parent is going to die, they expect it to happen the next day, and it can be quite hurtful for the person who is ill if the little one sees them next day and asks: 'Why aren't you dead?'

It's better if the parents tell the child that Mummy is 'poorly', and that the doctors are giving her medication to try to make her better. If she deteriorates, that is the time to tell the child what is happening. If they ask outright if Mummy is going to get better and you know she definitely isn't, then they need to be told the truth. If they ask when Mummy will die, tell them she will be here as long as she possibly can. And if you don't know, say so.

We all have to take it day by day. It's about getting the balance between being truthful and allowing the child and parent to enjoy the life that is left to them. It's important not to take away that time. They don't always want to be talking about dying; they want to make the most of the time they have left to live. People quite often live much longer than they expect, and that is why we have to be so careful what we tell the children. The conversation has to happen but with younger children it shouldn't happen until they can see their mum or dad is actually deteriorating. To me, someone is living until they are actually dying. It's only

when the process of death really starts that the child needs to be told.

When I first meet the child I explain why I'm there. I am very clear – I say I'm there because someone is ill in their family; that sometimes it can be quite difficult because it changes things; that my job is to be there for them so we can talk about what it's like for them, but we will also talk about good things, and what they like. But I am also very clear that I will always take things back to mum and dad. My role is not to act as a go-between but to make sure that the children are in the communication loop. For instance, if a child says her mum is coming home from the hospice the next day, but I know the mother isn't coming home, and very probably won't be, I will contact the parents and tell them that the child is two steps behind everyone else in terms of what they know.

Children can so easily misunderstand what is happening if it isn't explained clearly enough for them. Say the parent has a brain tumour and has gone into hospital for treatment. The child may think that it's their fault because they were asked the night before not to make so much noise because Mum's head was hurting. Or the other parent may say Mum has gone into hospital and is fine now, and the child may think she's fine because she is away from them. Children need to have things explained to them clearly so they know what is going on.

If the parent is quite poorly I might see the child on a weekly basis to build up the relationship. But you can't talk about death and dying all the time, so usually I see a child monthly. Sometimes the family will want me around more when the person is dying. Having me there gives them more confidence, but the majority will be able to manage as a family – that is what I am aiming for. After the initial contact, a lot of the work is on the phone, giving reassurance and offering advice.

Supporting teenage young people

With teenagers it is easier because they do think much more like an adult. I often meet teenagers at the same time as I meet the parents. I make it clear beforehand that they have to want to meet me, otherwise it will not work.

Teenagers need to be told what is happening, but they probably won't react in the way adults expect. They will still want to go out with friends and do the things they usually do. They might not even tell their peers what is happening at home, or they'll tell their best friends but won't want it to be widespread knowledge.

Most teenagers don't want any fuss at school – they just want to be treated as normal. I encourage them to tell the teaching staff – I suggest it can be helpful if they are struggling with homework, which can be the case, especially if they're spending a lot of evenings at the hospice with their parent, or they are having difficulty concentrating. I can also arrange pass cards for them so they can leave the class if they get upset – for boys, that's often a big issue. They worry about getting upset in class. Girls are more likely to have a support network of friends they have told.

It can be helpful for the teachers to know. They may have noticed the young person is a bit distracted in class. Even if they do know that the parent is dying, often teaching staff don't know what to do or say. I will work with the school to try to help staff to communicate with the young person so they can find out from them how they want the situation to be managed. A big part of my role is bridging work – I instigate things and leave it to people to manage it themselves.

A very big issue for teenagers is fragmented families. These days, it's more common that the person who is dying is with another partner. So, when they die, the children may have to live with their other birth parent, whom they may hardly know and who is likely to have their own second family. Sometimes the death means that both birth parents are dead. It's very hard for everybody if the children have to go and live with another family and I have to work with both sides. But I find that most families unite at that point, even if there have been tensions and difficulties before. Sometimes that is where my bridging role comes in too. I might take the children to the house where the parent who has died lived so they can collect something for their memory box.

Do-Good's role

Do-Good is a way of breaking the ice. I got him by chance. A colleague at Seesaw had some puppies and wondered if I'd like one. I live in the country and love walking but I was really quite afraid of dogs. I'd never had one in my life. My Seesaw colleagues persuaded me that it would be a good thing. Then of course I realised I'd have to bring him to work, and from there sprang the idea that having a dog might actually help my interactions with the children and might help them feel at ease with me and more able to talk to me. It was quite fraught to begin with, when he was still a puppy. We had to grow in our relationship, but it's a splendid working partnership now.

Do-Good is a labrador–collie cross. He's a big dog, but very gentle. I always check first that the children aren't allergic to or afraid of dogs. Very few children don't want to meet him – even if they are a bit scared, they will still come out for a walk with us.

There's no great science behind it, but it does seem to work. Do-Good knows he is there to be with the children – he ignores the adults. That is what he's been trained to do. Often the first meeting is all about Do-Good. I think it gives the child back some control over something in their life – they can tell him to sit, feed him, hug him, and he gives them a paw if he's asked. He's also a distraction – taking him out for a walk takes the pressure off. When you are walking you are not face-to-face, looking at each other, and Do-Good is between you, so I can glean information from the children while we are also just having a fun time. It's that combination that I find helps children to be able to express what they understand about what is happening.

And he really does appear to understand the children's needs. An example is one family where the father was dying and the young boy did not want to go into the room where he was. We went out for a walk with Do-Good and the child told me he was afraid that his father was going to die there and then when he went into the room. We talked about it and I reassured him, and the boy was able to go in to see his father and say his goodbyes. When he came out he sat down and began to sob and Do-Good went up

to him and put his paws around him and licked his face. Normally I wouldn't allow him to do this, but on that occasion it seemed right and fitting.

People often ask if Do-Good works as an icebreaker with teenagers too. My experience is that most teenagers want to engage with me, but if they like dogs, it's easier to be seen in the street with somebody who has a dog. You can always tell people who see you that you were out walking the dog, and they can show Do-Good off. One of the best bits of feedback I've had from teenagers was: 'It's great to have somebody like Kathy who you can talk to and who is there for you but that Do-Good is the icing on the cake.'

Helping families

People often ask if I think my work makes a difference to a family and I really do think it does. If the family can start talking about difficult issues before the parent dies then the doors will be open afterwards. One of the things I work very hard at is helping families communicate with each other. That is why I bring information back to the family and to the young person about what is happening and how it's happening. What I want is that, when the child grows up and if they're in a difficult situation, they won't think they need to come to me for help; they will know they can go to their surviving parent. ■

'Do-Good doesn't mind if we are crying'

This is some of the feedback Kathy and Do-Good have received from the children and parents they have supported:

'I was really worried about meeting Kathy and thought I would be so sad, but when we saw Do-Good we just wanted to laugh and have fun.'

'Do-Good doesn't mind if we are crying. We don't have to tell him why, we can just start playing with him and feel happy again.'

'Do-Good means to me we are not just saying sad things or doing sad things. He cheers you up and he calms you down and makes you feel happy. He's funny. I love him.'

'Do-Good really did help to break the ice for all of us ... [His] picture remains on all of their bedroom doors and I know that you are both very important to us. No matter how low I am feeling, when I see the children so pleased to see Do-Good, take him for walks and watch his tremendous ball skills and tricks, it reminds me that we can still feel happy.'

'Ever since my Dad passed on Do-Good and Kathy have helped us through the bad, awkward and most difficult of times. We have always come through on top. My life since it happened has been incredibly difficult. I have now had to spend two birthdays without him, one Christmas and one New Year party. But the biggest challenge was having to change schools from primary to secondary school, all by myself and without him supporting me or being by my side. Anyway, now I have met Kathy, Do-Good and Seesaw, I have coped much better than I thought I would. Thank you Kathy and Do-Good. Thank you Seesaw.'