## CHAPTER 6

# What Does It Feel Like to Experience Narrative Therapy?

### USING NARRATIVE THERAPY TO HELP NAVIGATE THE JOURNEY IN BECOMING A DEMENTIA CARE PARTNER

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We, Karen and Rosslyn, have known each other through the Cardiff and Vale Young Onset Dementia team for several years. We met initially when Karen's husband, Nick, requested help following his diagnosis of Alzheimer's disease at the age of 55 and asked if there might be any support for Karen.

We have worked together in different ways, reflecting the different needs Karen has had as her and Nick's situation evolved and changed. More recently, we have reflected on what it has been like to work using a narrative therapy approach. We share a passion for improving the care of people living with dementia and their supporters. Rosslyn has talked with Karen about the lack of research and literature relating to using this approach in dementia care, and together we felt we could play a part in improving this by sharing our experience with others.

In this chapter, we hope to share our experience of using narrative therapy in a way that assists both supporters/carers and clinicians in understanding both how this approach works and how it can be helpful. We also hope it might be helpful to people living with dementia, who may be looking for ways to support themselves in connecting to helpful stories of identity, as well those who support them.

We thought it would be helpful to discuss the following:

- How it felt to Karen being offered psychological therapy and what helped her to get started.
- Some of the emotional and psychological aspects of being a carer of someone living with dementia.
- What using narrative therapy looks like.
- What it is about narrative therapy that might be particularly helpful to carers of people living with dementia.

First, a note about terminology. We recognise that people caring for someone living with dementia and people living with dementia have different preferences for the term we use to describe the person in the caring role. Karen uses the word 'carer', so we will use this term in this chapter.

### Getting started with narrative therapy

### Karen

It was Nick who requested support from psychology initially. He had a sense that this would be helpful. At that time, he was still working and we couldn't be open about his diagnosis. Nick was getting support as a patient, and I was included alongside him, but I wasn't offered this personally. He asked: 'Is there something you could do for Karen?'

I knew I needed something. When you're a carer you're still mentally okay, but the person with dementia isn't and you automatically take on the care and support of them. At the same time, you're trying to feel your way through this forest of the unknown – What's ahead? What's around? No one could tell me how long it's going to last, and it's so difficult to understand the condition itself. This made it difficult to work out how I could accept this diagnosis, what it is, how should we tell people and so on. There is a stigma around dementia, especially at 55. People don't know how to approach it, especially when no one can tell you what the outlook is. All you know is that someone has pulled the rug from under your feet, and you are struggling in a very isolated way.

Although I knew I needed something, I didn't know where to find it. The literature isn't very helpful. It tells you about all the practical things, but what I needed was help in coming to terms with those deep emotions, and I had no idea what that would look like. In our case, it felt unhelpful that the literature is mostly written for people diagnosed in older age, which added to the sense of stigma. I had received an appointment on formal NHS paper inviting Nick and me to an appointment with a psychologist, but I was thinking, 'What are we going to? Are we going to be labelled?' It's slightly unnerving to get NHS letters anyway, then there's the stigma about psychology and psychiatry too. In the back of my mind, there was all this American stuff about 'going to see my shrink' and lying on a couch. I went not knowing if it was a test or not. Someone like me has no idea of what psychology is or how it can help.

We went to a strange little room, and it did feel odd for a while. However, Rosslyn explained things. She and her colleague were welcoming and kind, and I realised this was not an inquisition. They helped me to understand the safety of talking with them. I understood that our conversations would be confidential, and I could see that they were professional, well-trained and sympathetic. I could feel that they were not going to be judgemental. I understood from them that this was support for me rather than any kind of medical intervention.

## What using narrative therapy looks like

### Karen

At the beginning, what helped was a psycho-educational course for dementia carers called START (STrAtegies for RelaTives programme; Livingston et al. 2019). It helped me to know I was being given something solid that had been developed by University College London. There were helpful suggestions in each unit, and I felt as if I was learning. Doing an individualised course, where I could talk about my experiences in this structured way with a trainee psychologist, was helpful in the first instance, as I could get used to the idea of opening up and feeling comfortable with someone else in the room. It was helpful for me to be able to see the development in my understanding over time. It helped me to learn strategies, especially around relaxation and mindfulness. For me that was a really good introduction.

For a while, I was able to use the strategies I had learned with START to carry on caring for Nick, and that felt like enough. However, over time, the doctor realised I could do with a bit more help. She would meet Nick and me every 6 months for a review and arranged to have some one-to-one time so that I could speak openly. She asked how I was coping with life at home. I found it quite emotional, and when she asked if some further psychological support would help, I knew that it would. Although I had done the START course with psychology before, I didn't know I could ask for it. I'm not sure I would have asked for it if I'd realised it was available. Maybe I would have done, but I was brought up to cope if you can. There was a sense for me that I didn't feel I deserved it: I know how stretched the NHS is, and Nick is the patient, not me.

## What using narrative therapy has been like

### Karen

Your full-time caring commitment leaves you very little room to think too much about yourself, but actually it's very important to give yourself some time. It's difficult to find and there's so much to do. This hour I have, now just every couple of months, is reassuring. It's just for the carer, it's not for the person you're caring for. It's an hour just to spend on yourself and come to terms with what you are really thinking and feeling. A lot of the time you are suppressing those thoughts in order to cope. This gives you a chance to let go of all those inhibitions and let the emotions flow. I can say why caring can feel so irritating or why it's so sad or terrible. I'm speaking to somebody who is a professional person, who isn't just a friend and who isn't going to judge me. Rosslyn is there to support me rather than say, 'Why don't you do this or that?' or 'I know'. You have a listener for yourself for an hour who is actually helpful in asking questions to allow you to explore your own thoughts and own ways of managing. By the end of an hour, I feel like my situation is clarified each time. I feel quite drained, but I feel I can carry on. I can continue. I feel like I have been helped to get to grips with the emotional reality of the situation and its life-changing effect.

### *Rosslyn*

One of the things that got me thinking about writing this with Karen was a comment she made at the end of one of our sessions when she said, 'You ask the right questions'. I remember trying to explain that the questions came from her. This is where narrative practice feels so helpful and feels different to other approaches I have been trained to use.

When I first did my narrative training, I recall the surprise at hearing that 'Wherever your conversation gets to should be unexpected'. As psychologists, our usual approach is to formulate what you think the problem is and hypothesise as to what will be helpful for the person you are working with, guiding them through sessions to get there. In narrative therapy, we are trained to resist hypothesising. As we discussed in Chapter 2, there is an idea that we assist someone to move from what is 'known and familiar' (the well-told narratives) to the 'possible to know'. We do this by listening very carefully, perhaps for exceptions to the problem situation, perhaps for discourses that might be leading someone to feel stuck, perhaps for something that is implied but not said explicitly. These are all things that can be available for the person to think more about but may not be fully evident to them in that moment – 'possible to know'. So, when I ask Karen 'the right questions' I am delighted. I do not start out with a plan or idea as to what those questions will be, but if they feel right, it's because I have managed to hear what she needs me to.

On many occasions, I will hear a range of possible things I could ask about. For example, I might say something like, 'I'm interested in asking you more about what you think about staying at home more, but I'm also wondering about this issue of feeling guilty. Which feels most relevant to you at the moment to talk about? What do you think is more important today?'

### *Karen*

When I come to the sessions, I often have very little idea of what I need to discuss. It has seemed to me that sessions are much more structured, that Rosslyn had some kind of plan or knew where we were going. At the end it feels like there's been a plan. I feel, 'That's spot on; that's what I need'.

### *Rosslyn*

Although I do not follow a plan for what we will talk about, I do use a structure to help frame our conversations, using Michael White's (2007) 'maps', as explained in Chapter 2, to guide our conversations. This helps me to follow some of the key principles of narrative therapy we have discussed, such as encouraging rich, detailed storytelling about the situation and assisting Karen to name and externalise a particular problem. This can also help her to establish her position on a challenging situation, as we can discuss why Karen may feel the way that she does by considering the situation in the context of her values and her family and social environment. From my perspective in working with carers, the ability that narrative therapy gives me to consider the wider 'social discourses', as discussed in Chapter 3, feels important and distinctive about this approach. There are frequently ideas around duty, or expectations about caring, relationships and different roles, which are linked with things such as gender, class, culture and religion, which can often be helpful for people to notice and give thought to.

Karen and I have spent time thinking about this in various ways. For example, Karen has often shared a sense of failure about not 'doing more' in relation to social activities and engagements. Both she and Nick lived busy lives before dementia. She has noticed that the times Nick and her are happiest together is at home, maybe sitting in the garden or listening to music. Despite having learned from Nick that taking things more slowly and keeping to a routine works better, she has still had times when she has doubted herself, wondering if she should be 'trying harder'. There has been a nagging doubt that perhaps she is being a bit lazy or 'staying too much within her comfort zone'.

I have understood that there can be different pressures here. One is the 'use it or lose it' idea, which gets Karen worrying that maybe she is not providing enough stimulation for Nick. Another seems to be around 'living life to the full'/'making the most out of life', which seemed to connect with discourses in her social group about how retirement should be, as well as wider social discourses connected to coming out of the pandemic. These created a sense of pressure for Karen that she should be doing more – travelling, social engagements and so on. Having a way to tease out where these ideas come from has felt important. In doing this, Karen has had space to consider what she feels about these ideas, and how they might fit with the values and preferences she holds for her life and for Nick's.

There have been some discourses, such as the importance of learning, that fit for Karen. Together, we have traced the history of this in Karen's life, linking it to family values and her choice of career as a teacher. At an earlier point in our work, she was able to see pursuing opportunities for learning as something she could think differently about. She and Nick were learning to dance together and that could be enough. More recently, however, as time passes and Nick is less able to join Karen in learning new dance steps, we have returned to this. While it did not feel right for Karen to pursue her own interests and learning at an earlier stage, when Nick was more able to join her in activities, this has changed. Using a narrative framework for our conversations has assisted me in finding ways to help Karen 'deconstruct' or think about the different factors that influence her thinking and decision-making about this, to weigh and consider them, and to go on to identify a way forward for herself.

### *Karen*

These conversations clarified the current situation and 'gave permission' for me not to have to strive for more in the current situation and the confidence to go forward in these different ways.

> ### How narrative therapy helps
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> ### Karen
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> 'Living well' and being positive is great for the person living with dementia. Nick has always been very sociable, and he can participate in groups and

> activities that are offered to him. But for the carer, you're in a dementia world and you don't have dementia. So, actually, living well is quite a false way of life for the carer. It's a way of life that you have to accept. It's as if you have been given crutches; you have to take on the dementia yourself in order to enable the person you care for to live well with it. For example, we joined a trip to Porthcawl recently; it was lovely, and I embraced it, but I had felt, 'I want a trip to Paris or London'. Of course, the dementia world can help me as a carer too; you form a parallel world that you can become quite comfortable in, but the carer has another life that mustn't be ignored and that can be difficult to find.
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> It is easy to be consumed by this one aspect of identity – 'the carer' – when previously you have enjoyed a range of diverse roles – wife, mother, professional, social roles. You have to be aware that you are losing some of these aspects of yourself in order to preserve the ones that you feel you need to be recognised for now. Just having a chance to talk and express myself to Rosslyn, an unbiased professional, helps me to understand how my sense of self is affected by the (passive) dementia, now that Nick is no longer able to hold a conversation with me in the same way as we had previously enjoyed. Just the chance every few weeks to speak and express my identity helps. I appreciate being asked what it's like to try and untangle the different pressures on how I should be managing – what do I really feel and what do I want to do? – and to pinpoint what the external pressure actually is. This often helps me to let go of the things now that I just can't do and provides the means to explore how relevant those roles I can no longer fulfil are.
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> An illustration of this loss of opportunity are the plans Nick and I had for the time when the children were off our hands. We had hoped to spend weekends away to enjoy our interests, such as going to the theatre, visiting galleries, trying new restaurants and so on; we were looking forward to a more relaxed social life. This is no longer possible at this stage in Nick's dementia as any outing requires thorough planning and risk assessment. The fact that life has become so restricted for me is a grief in itself. I experience a huge sense of loss. The fact that our friends and family are enjoying the lifestyle we had looked forward to only exaggerates this sense of sadness and frustration.
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> The misguided advice I often receive from others in their attempts to

> be helpful in encouraging me to participate more only adds to the problem. The therapy sessions provide huge support in dealing with these emotions and pressures. I am offered the opportunity to explore the activities that I feel are currently denied to me. I can allow them to be put on hold for the time being rather than letting go completely. This helps me to manage the frustration of not being able to live the way I would like to. It also gives me the space to appreciate the rather alternative life I find myself leading and enrich it with a range of experiences that are still accessible to both Nick and me, as well as developing hobbies for myself which can be fitted around my caring responsibilities.
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> Another example of the grief of not being able to fulfil a role I care so much about is the time when my eldest daughter had her baby, and I couldn't go to visit and support her just after the birth. I felt overwhelmingly angry that I could not fulfil my role as mother and grandmother. I felt entirely trapped by my circumstances. Nick could not understand. It was a very difficult time for me. My youngest daughter was able to be with her sister and did a fantastic job. It actually had no consequence that I was not there, as both daughters were highly competent and both understood entirely why I was not able to help. However, I found it extremely difficult that I could not provide the support I longed to offer or to share at first hand the joy of a new baby. It was very helpful to speak about the resentment with Rosslyn. It helped me to deal with those feelings of frustration due to the incapacity to act, the anger and the grief. By putting it all into perspective through our discussions, I was able to come to terms with the situation and to banish the blame I had put upon Nick.
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> For me, being able to talk in this way is a release. You can experience that in other ways, like watching a sad movie or going for a long walk. It's almost like a physical way of dealing with those emotions. Because it's a huge sadness to watch someone go through dementia; it's grief every day. It doesn't change things dramatically, but I feel refreshed and ready to carry on and continue. On the whole, I have to suppress the grief in order to maintain normality, but it doesn't go away; it's there and you can't deny it. And those sessions allow you to acknowledge it and say, 'Yes, this is terrible'. I feel a sense of well-being from having taken the lid off. Everything is calm afterwards. Without the opportunity to talk with Rosslyn, I would feel a lot more frustration and anger and a sense of entrapment. If I didn't

> have time to explore these feelings, I wouldn't be able to stay calm. There are times when I do lose my temper, but it doesn't happen very often. Without this, I think I would be overcome by that a lot more, and that would certainly affect Nick. He becomes defensive if I'm angry and this creates conflict. If I can remain calm, it keeps the situation manageable and more enjoyable for him. If he picks up my frustration or sadness, he can become anxious and can't understand, and that can create other conflicting emotions, as I still have the anger but it's due to grief.
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> Without this therapy, it would be harder for Nick and me to go forward together. This applies to managing my anger and frustration but also my grief. Grief is always there and doesn't go away, but I can't give in to it with Nick as I don't want to create a sad or depressed atmosphere; I want to maintain a warm and comfortable relationship. This grief has to be acknowledged, and it can be managed in the sessions. Sometimes, there can be a day or two when it can feel overwhelming, and I can feel like I can't go forward. Being able to talk about it provides a strategy to accept it, give in to it sometimes and then find positive aspects to our relationship. Although grief is always there, there's still a lot of enjoyment that can be found. And sometimes you have to laugh and see the funny side of it all.
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> I don't go in knowing what I'm going to talk about; this is the weird thing, except when there is something very practical and very physical. On one occasion there was a practical side – toileting issues – which was upsetting for me. And it helped that Rosslyn is part of the team caring for Nick as there is practical backup there as well; I know she would put me in touch with the right person if that's needed. So, it's different to an anonymous psychologist who doesn't know the background, and there is a trust that comes from Rosslyn being part of the team, which also helps. In that instance, I needed to be able to talk about my horror about managing toileting but also the practicalities. This situation was an example of me finding I could cope with something I thought I couldn't, and therapy helped me through that. Now I can look back and see how I adapted. I still don't know how I will cope in the future; I just think about the present. The sessions help me concentrate on this, along with the grounding and the mindfulness I learned from the START course.

### *Rosslyn*

I think Karen makes an important point here about how using narrative therapy fits within the broader service context in which we work. The philosophy of narrative therapy is one which places the person and their knowledge of what they need at the centre. If then at a particular point in time, what that person needs to do is to step outside of more reflective work and to think through some practical strategies, this is possible. What is important is to talk explicitly about what the person needs at that moment and to offer some ideas that can be talked about, while acknowledging that this may mean a bit of a gear change or different type of conversation. Strategies that I have offered to Karen, such as in the toileting situation she references here, are shared in the spirit of collaboration rather than expertise – for example, 'I've found that other carers have found this idea helpful. Would you like to hear more about it?' This feels like an important difference from advice-giving. Karen's reflection additionally helps me to understand the value of coming to this work as part of a multidisciplinary team and as a therapist who also has knowledge and experience specific to dementia care that I am able to share, as opposed to seeing a generic therapist in a mental health or primary care setting.

So often, I find that care partners bring to me a dilemma about managing their own needs alongside those of the person they care for. Narrative therapy has helped me to find ways to fully explore the nature of these needs in a different way. Rather than stopping at personal preferences or taking the idea of needs at face value, it asks *why* these things might matter. We can ask for the stories in someone's life that help us to understand where those needs have come from. It feels that this is helpful in enabling someone to see that something they've always believed to be absolutely necessary, or a duty they have never questioned, is simply an idea that may or may not be true for them. It may or may not be something they want to continue with in their life. This can have the