

Dementia: caring for the couple



Dementia affects couples as well as individuals. **Andrew Balfour** describes an intervention that recognises the importance of relationships and of working not only with people with dementia but also their partners

More than 30 years ago, when I was beginning my career as a clinical psychologist, I had the task of giving an elderly man a diagnosis of dementia. I had nothing to offer him and his wife, except an information leaflet. I have never forgotten the image of the couple leaving the hospital, holding onto each other as they walked through the grounds in the rain.

It's now three decades later, and not much has changed. Although there are more psychosocial interventions for early-stage dementia, availability is inconsistent and limited. And few of the interventions that are available recognise dementia as an illness that affects not only individuals but also relationships. Yet around the world, most people who have dementia are looked after at home by their spouse or partner; only about 30% ever go into residential care.¹

Several researchers² suggest the need to recontextualise the experience of dementia as an illness affecting relationships rather than individuals. It's a conceptual shift that supports the development of services and policies geared towards encouraging togetherness rather than separateness – and focusing on family systems rather than individuals.



Dementia is an umbrella term for a range of progressive conditions that affect the brain. Each type of dementia prevents a person's brain cells (neurones) from working properly in specific areas, affecting their ability to remember, think and speak. There are more than 200 subtypes of dementia, according to Dementia UK. The most common are Alzheimer's disease, vascular dementia, Lewy body dementia, frontotemporal dementia and mixed dementia.³

In 2019, there were an estimated 748,000 older people living with dementia in England; this number is predicted to grow to 1.35 million by 2040.⁴ The London School of Economics and Political Science estimated the total cost of dementia in England in 2019 was £29.5 billion – and it is expected to increase to £80.4 billion by 2040.⁴

wellbeing of the carer or partner than factors such as severity of the disease. Indeed, studies show that the quality of relationship in dementia is of vital importance. For example, there is evidence that insecure attachment in people with dementia, as well as their caregivers, is related to higher levels of behavioural and psychological symptoms in dementia.¹¹ Research also shows that dementia impacts on spousal relationships by causing decline in communication, opportunities for shared activities and happiness.¹²

‘Protective aspects are to do with emotional contact and understanding’

Studies show that providing carers with emotional support earlier on delays subsequent admission to residential care of the person with dementia by an average of 500 days.⁵ Indeed, research has found that low levels of positive interaction in the marriages of people with dementia predict the move to residential care and the death⁶ of the spouse with dementia two years later.⁷ Closer relationships between the carer and the person with dementia are associated with slower decline in Alzheimer's disease, and this effect is highest for couple relationships.⁸

Many people are looked after by their partners at home, at least in the early stages of dementia. Efforts in health and social policy are also, at present, directed towards encouraging home treatment. Carers of people with dementia save the taxpayer £5 billion a year, according to a report to a Public Accounts Committee. The committee was also told that carers do not get the support they need and many feel abandoned after the diagnosis. The burden of cost on the carer is more than economic, with the role placing ‘...a mental and physical burden... leading to poorer outcomes and health inequalities’.⁹

Partners of people with dementia are usually the carers who experience the heaviest burden,¹⁰ often suffering from stress and burnout. At worst, unsupported carers in difficult and pressurised home situations can, in some cases, act out violently or become neglectful.

The maintenance of the person with dementia in the community has more to do with the attitudes and



Health and social care professionals are often aware of the impact on the partner, but they generally have little training in working with such couples. At Tavistock Relationships, we've developed a structured intervention, *Living Together with Dementia*, that draws upon psychoanalytic thinking and approaches developed in working with parents and children.

Protective aspects of relationships

Our aim is to help people with dementia and their partners to manage the trauma of the diagnosis, the loss and the changes it brings, and to help the couple to maintain, or recover, the protective aspects of the relationship. Research indicates these protective aspects are to do with emotional contact and understanding, shared activity and involvement, as well as the overall quality of the relationship. The capacity of the couple's relationship to function as a protective factor, and as a resource that can survive and contain the care needs of the person with dementia, depends on the resilience of the couple and on finding ways to support this resilience.

In the post-diagnosis phase, the initial emphasis of assessment and intervention is on engaging the couple, exploring their experiences and containing their feelings. Couples might have to manage considerable anxiety, and dementia might carry the threat of being abandoned to a state of utter helplessness. At an unconscious level, this might evoke fears of a traumatic return to earlier states of dependency.

When considering the mindset of the carer, we can think of the Bion model of containment.¹³ In the original developmental model, the mother takes in and processes the infant's experience. The mother then conveys the understanding back, so that unmanageable experience is rendered more digestible. Waddell¹⁴ points out how this can be transposed to the situation of dementia care – where windows of clarity, of a briefly more integrated state, might be opened for the person with dementia, when the carer partner is able to make emotional contact with them.

Acknowledging and sharing difficult feelings

It is important to recognise the tremendous challenges facing the carer and not to idealise what is possible. The carer might have all kinds of feelings towards the individual with dementia in their care. They might feel compassion, but they might also feel resentment or hatred. These feelings might arouse guilt or anxiety, and the carer might need help and containment. Generally, however, interventions with carers do not address this more difficult area. As one person said to me: 'There are images of rosy carers on all the leaflets – but it's not like that... I hate her a lot of the time and it's sh*t – and it's like no one can tell the truth – how sh*t it is, and the resentment... What do I do with that?'

People often lack a way of thinking about or making sense of their feelings, particularly feelings of guilt and shame, and have no one to talk to about their emotions. It is therefore important for the carer partner to have the opportunity to have another take them in, to listen non-judgmentally. It can be a valuable experience to be able to use the therapist in this way, as someone who is able to acknowledge and understand feelings that might arouse shame.

In a relatively healthy adult relationship, where projections are not too fixed, partners might be able to act as containers of difficult feelings for one another in a flexible way. But in a relationship where one partner has dementia, the burden will increasingly shift to the partner without dementia to act as container for their spouse. So, the couple loses a relationship in which they have provided containment for each other.

'People often lack a way of thinking about or making sense of their feelings'

Carer partners, particularly men, speak of this as a 'reversal': 'She looked after me; now I have to look after her, and I'm not good at it.' Or, as another man said: 'When we first got together, I used to be more shut off, and my experience of being with her helped me change. She's always been so thoughtful... now she shuts down. It used to be me who was the one who was more shut down. Now it has switched around and she is the one who is more like I used to be... now we are crossing over into opposite places.'

As the dementia progresses, the patterns might not simply be reversed or amplified; instead, there might be a complete sea change. The person with dementia might not only be unable to offer containment for their partner, but they might also be projecting something persecuting into them. So, loss is not simply an absence, but instead the experience of living in the presence of something persecutory. The carer partner is likely to be filled with their own feelings of loss, frustration or rage, so it is difficult for them to take in their partner's projections or state of mind.

Containment for the healthy spouse

The presence of a third containing figure, a therapist or counsellor, who will listen and not judge, can be powerful. The model is akin to a Russian doll: the person with dementia is contained by their partner, who is contained by the therapist, who, in turn, has the containment of supervision. The important thing is containing the container. In the pilot work we have done, our impression has been that, as well as prior

relationship quality, a protective factor seems to be the carer's capacity still to be interested in their partner's feelings and the ability to see meaning in their partner's behaviour, even when they might be behaving in a way that is quite disturbed.

I worked with one couple who gave a powerful glimpse of the trauma of the diagnosis. Since the diagnosis, and in the period leading up to it, Brian had been depressed. He said to me: 'When the diagnosis was made, we cried every day and then every other day – and then you kind of get on with it. What is so difficult is the hatred that I have for what is happening... for the people that don't have this...

Margaret's husband was in the more advanced stages of dementia. She felt that everyone expected her to be a saint, that they weren't concerned with the reality of her experience: 'No one's interested; they don't know what it is like,' she said.

Looking after her husband repeated for Margaret a version of her experience as an only child, when her mother developed profound mental health problems after the death of her father. Then, as now, she felt alone with a burden.

The marriage had always been difficult and, at times, violent. In recent months, her husband's dementia had progressed significantly – and he responded by getting increasingly annoyed. Margaret retaliated with irritation and criticism, replicating the angry exchanges that were familiar in their marriage.

The situation was worse when her husband was in a panic and feeling lost. I witnessed how she would tell him things that he could not understand or have the capacity to follow; he would respond by saying he did not know what she was talking about, that she was not making any sense. Margaret would then get angry and critical, as she 'heard' his response as his refusal to do things, as his deliberately being difficult. Her husband then became aggressive towards her.

It took a lot of work for her gradually to begin to shift her perceptions of such episodes, to think about what might be happening in his mind, to put herself, to some extent, into his shoes. Crucial to this shift was the therapeutic stance of listening and empathising with her feelings, so that she had the experience of someone trying to understand her perspective. Once this process was established, when she started to feel 'taken in' emotionally, Margaret began to allow herself to think more about her husband's experience.

the hatred that I feel in here (points to his head). I'm f**king angry... the hatred... it is so hard to have that inside you. I want understanding, but don't feel I get it. I can't manage the hatred and the rage.'

Under such circumstances, having a mind available to help the couple to think, process or understand their feelings, as much as they are able to, is crucial. Without it, partners might withdraw more from one another, and there is greater danger of acting out the anger, frustration or other feelings and anxieties.

Disruption of attachment bonds

The partners of people with dementia often talk about the loss of emotional contact and reciprocal communication within the couple. Some carers expressed this loss of communication as '...if only I knew what he/she was thinking'.

'The older couple relationship can be a tremendous resource'

As adults, we do not outgrow our need for attachment and security. It encompasses the whole lifespan. Indeed, attachment relationships are understood to be a protective recourse in later life,¹⁵ and they are particularly relevant in cases of dementia. The process of dementia can be characterised by experiences of loss and separation from attachment figures, and feelings of insecurity.

Miesen reports a high incidence of attachment-seeking behaviour in people with dementia.¹⁶ And Van Assche et al note that insecure attachment is related to higher levels of behavioural and psychiatric symptoms in dementia.¹¹

In caregivers, insecure attachment is associated with a heavier care-giving burden, negative appraisals of the situation and less satisfaction with perceived support, as well as increased incidence of anxiety and depression.

By contrast, secure attachment has been found to sustain the capacity for emotional contact between partners, making it easier for both people to accept the losses and changes that come with the disease.

Historically, there has been a neglect of the experience of dementia as a focus of study that could help shape our understanding of how best to help those living with the illness. We need to draw on what we know from research and clinical practice about the importance of emotional contact and containment in mitigating attachment insecurity and supporting

the person with dementia to be anchored in the world of meaning and human relationships.

The older couple relationship can be a tremendous resource, able to provide care that is costly to give in institutional settings. However, real support of the resilience of the couple and protection of this potential resource depend upon acknowledging the emotional challenges these couples face.

As counsellors and psychotherapists, we can recognise that lack of support for, or separation from, important relationships, as well as lack of emotional engagement with the person with dementia, can be profoundly damaging. Therapeutic interventions are therefore needed to help support relationships at this end of the lifespan. Our services need to become more relationship minded, to support the humanity of the individual with dementia and those around them, so that emotional meaning can be held onto within the environment of care for as long as possible. I think we would all wish for such an environment for ourselves and those we care about.

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