

# Dementia diagnosis and beyond: a counsellor's view

Following a diagnosis of dementia, counselling can be a helpful approach to facilitate communication and understanding, writes Mike Fox

I work as Lead Counsellor for Dementia at Age Concern Camden. This service offers counselling to people with mild to moderate dementia and also to those who live with or care for such people (typically partners or sons and daughters), for a period of up to a year. A high proportion of our referrals come from the local memory service, which means we see many people who have recently been diagnosed with dementia and/or others who are closely involved with them. This has given me the opportunity to build an intimate picture of some of the ways in which people respond to this life-changing news, and how – at this relatively early stage – they view the prospect of living with dementia.

In this article, based on what I have learned in counselling sessions, I explore the impact of diagnosis on people with dementia and those who live with them and become involved in their care. I reflect on some of the consequences of the progression of dementia. I also look at the effect dementia can have on a person's sense of identity and relationships, how people with dementia may try to cope with declining cognition, and I suggest ways in which counselling can facilitate communication and understanding.

## Assessment

The initial session – the assessment – is an opportunity to gain a deep holistic picture of the potential client's situation and to decide whether counselling might benefit them. For those with no experience of counselling, I explain what it might involve. This first contact offers clients an opportunity to speak in confidence of fears and concerns about a future that may suddenly appear far less certain. We may explore current support structures and suggest how to access further help. The session may also reveal aspects of the client's past experience that will influence how they respond to the inevitable insecurities that accompany the news of diagnosis.

Sometimes I am the first person to whom the client feels able to describe how the news of dementia has affected them. This may be because the person who has received a diagnosis, or the person who is living with them or who may become involved in their care, feels the need to protect the other by containing the strong feelings that the situation can evoke. They may also wish to shield third parties such as family members or friends, or may fear their

potential reaction. This is perhaps one of the first ways that dementia can affect communication between people who love and care for one another. This common problem highlights the value of an impartial and compassionate witness, and in itself validates counselling as a form of support for those affected by dementia.

## Response to diagnosis

I have been struck by the variety of ways in which a person may respond to their diagnosis. Some express an urgency to make the most of the time remaining, hoping to continue to live as normally as possible for as long as possible and perhaps to complete or resolve outstanding tasks and issues. In some cases this seems to represent an extension of long-held attitudes, and might indicate their way of responding to earlier crises or difficulties. For others, this approach seems to result from the stark recognition that the time in which they may function in the world as they have previously is finite and so must be cherished. In such instances tasks that might previously have been considered mundane can acquire new meaning, offering a way of demonstrating continuing areas of competence to self and others, or helping the person affected to maintain a sense of structure in their day or indeed of personal identity.

Sometimes diagnosis can prompt a time of introspection. This in itself can create difficulties, particularly as the psychological ability to shield oneself from painful thoughts and memories may be diminished by loss of faculty. Also, a person in the early stages of dementia may feel unable to sustain a line of thought long enough to express it to their own satisfaction. This may make them feel less inclined to share problems because they feel less able to articulate them. We speak about 'thinking things through', and by implication gaining a sense of resolution through attaining greater clarity or perspective about a situation or difficulty. This possibility is denied to someone who cannot retain a thought or idea for long enough or who feels unable to link thoughts coherently. Where this is the case the desire to explore, express or understand remains unsatisfied and the matter that demands attention or causes worry or concern, unresolved. A person in this situation is deprived of a normal means of processing and therefore is likely to accumulate



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problematic feelings. Similarly, dementia can have the effect of preventing the possibility of resolution that retrospection can offer. The opportunity to reflect on past experience and view it from a more detached perspective is inevitably diminished by memory loss, although I have found that this remains possible for those whose long-term memory is relatively unimpaired or those able to access specific significant memories.

### Effects of communication problems

Clients experiencing unaccustomed difficulties in thinking and self-expression often report feeling embarrassed or self-conscious, because they feel that these changes are nakedly apparent to others in social situations. In counselling, it can be very apparent that confabulation, although more frequently encountered in the later transitional stages of a dementia, can represent a compensatory activity – a way of trying to retain a sense of continuity in the attempt to communicate. At other times it seems to represent an attempt to disguise confusion or embarrassment, especially if the counselling relationship is relatively new. Doubtless it also offers the person who is struggling to describe their experience a way of sustaining an otherwise fractured narrative, and hence the ability to converse in a way that continues to be personally meaningful.

Clearly the desire and ability to communicate has great significance. It is well known that people with dementia are particularly susceptible to depression, and the build-up of unprocessed feelings that are denied expression can be a powerful contributory factor. Furthermore, it is natural for a depressed person to display less interest in their environment. Therefore, depression that follows diagnosis can increase any tendency to psychological withdrawal that may have existed in a person before the onset of dementia. The ensuing sense of isolation is likely to exacerbate further both the depression and any disinclination to engage with others.

This highlights a common paradox: dementia typically creates a distancing effect at the very time that the person experiencing its effects feels in greater need of support. Partners may also feel very alone, feeling no longer able to confide in the person to whom they would have turned most naturally in times of difficulty. As well, witnessing at first hand the enormity of dementia and its implications, they may empathise very closely, and struggle to distinguish their loved one's confusion from their own. It is not uncommon for a partner coming to counselling to seek reassurance that they themselves are not developing dementia, even when there are no external signs that this might be the case.

## *A person with dementia can continue to relate to significant memories in a way that is vital and dynamic*

### Memory

Inevitably, counselling people who have dementia or who are affected by it will involve discussion and exploration of memory as a theme and as a personal experience. We usually think of dementia as an illness which erases memory and memories, a process of increasing forgetfulness, but I have also observed that salient memories can appear to become more vivid and acquire greater significance, albeit perhaps temporarily. Where this happens they can sometimes become a focal or reference point to which the client returns, indicating both the subjective importance of the life events they represent and the confidence that their vibrancy and the fact that they remain easy to access appears to inspire. A life event and associated story that is easily and clearly recalled can offer the narrator a way of anchoring or finding a bearing amidst the instability and impermanence that results from short-term memory loss.

What is remembered and how it is described inevitably says much about the client's perspective at a given point in time. Memories are shaped not just by cognitive faculty but by the person who remembers and the context in which they remember, and the emotional context in which memories are revisited can change during the course of a counselling session. There is healing potential in the fact that our subjective perception of a remembered event can be easily coloured by mood. For example, a client recently described the same event twice in a session. Both accounts were factually identical. In one instance he remembered the events with regret and in the other with wry humour – suggesting that, temporarily at least, some resolution had taken place. This and other similar experiences suggest that the ability to heal past hurt is dependent on our perspective at the time of remembrance and that a person with dementia can continue to relate to significant memories in a way that is vital and dynamic.

Nevertheless, dementia inevitably lessens choice about the way in which memories, autobiographical material and hence a depiction of the person we believe ourselves to be can be presented to another. If we have fewer memories available, or if

we are less able to describe them, we lose possibly the most valuable context for portraying our identity, and so our sense of who we are is diminished. It is therefore vitally important for a counsellor to make every effort to meet each person with dementia on their own terms and to affirm and facilitate attempts to communicate.

In this context paraphrasing can be a valuable means of enabling greater clarity and mutual understanding. Paraphrasing involves restating what the client has said using different words. This fundamental but subtle skill can be used by the counsellor to reflect back in a considered way their understanding of what has been spoken or perhaps implied non-verbally by the client, allowing the client to agree, disagree or qualify. It can be used to explore what meanings a statement may contain and, to ensure that the client feels that they have been heard accurately, or to expand or elaborate on a point to refine meaning and attain greater mutual understanding. This can be particularly helpful for people with word finding difficulties, as the vocabulary they are able to understand will often exceed the vocabulary they can readily employ. Used sensitively it can enable clients who might otherwise struggle to articulate and share their experience in a way that continues to be meaningful to both speaker and listener.

### Repetition

A final and perhaps obvious point is that, even in the early stages, counselling people with dementia will involve working with repetition. When people become aware that they are unintentionally repeating a phrase or story, they may grow self-conscious or reluctant to speak, particularly if they have encountered irritation or even ridicule from others. However, repetition is important because of what it can signify. Where it is accompanied by noticeable emphasis it may represent an attempt to describe those attributes or experiences that the client feels most define how they feel or wish to present themselves in the present moment.

It can also be a way of conveying powerful emotions that attach to a particular event, and of ensuring that the personal importance of the event and the feelings it evokes are made known. Where this is the case it can indicate unresolved issues that are repeated in hope of resolution, in which case, as already suggested, it is important to be aware of any qualitative change in the manner of repetition. At its most fundamental I believe it can also represent the continuing affirmation of identity or assertion of self, allowing the counsellor to maintain and convey their recognition of the individual before them. Perhaps this is the most powerful gift counselling can offer a person with dementia.