Enabling people with dementi

Mike Fox puts in a plea for longer-term support for people with dementia and argues that often it takes the involvement of a third party to facilitate a helpful counselling process for a person with dementia

Mike Fox is the senior practitioner of a counselling service in north London where he works with older people who have alcohol problems.

Although a small number of services and individuals have begun to offer counselling to people with dementia within the last two decades, this valuable field of therapy remains in a fledgling state. There is still relatively little specialist literature available to develop a theoretical basis from which to work.

What we do know already is that, to be effective, counselling work with people with dementia must be both innovative and tentative. It involves developing skills and pathways to enable cognitively impaired clients to participate and benefit as fully as possible, while remaining mindful that, depending on the individual impact of the dementia, much may remain unknown about the inner world, personal history and even day-to-day circumstances of the person sitting opposite. Sensitive attunement and a willingness to try different approaches are vital to enable and maintain effective communication and to build mutual understanding of each client's perspective and situation. This inevitably requires both time and patience for both parties.

In this article I would like to consider two factors that I believe are necessary to offer this vulnerable and unique client group the greatest chance of using counselling effectively: first, the helpful involvement of third parties (such as a family member) and second, the importance of being able to offer longer-term counselling.

Help from a third party

Although counselling is normally viewed as an essentially private activity, there are a number of reasons why a third party – say a partner, family member or carer – might be more involved than is usually the case in generic practice, both at the beginning stages and as the counselling relationship progresses. People with dementia rarely contact counselling services independently and are very likely to need help to find appropriate support, not least because of the current scarcity of dementia-specific services. Even when such a service has been identified the potential client may need further assistance to access and continue to use it effectively where memory loss, diminished confidence or physical frailty might otherwise prevent this.

Of course the momentous implications that accompany a diagnosis of dementia are likely to provoke a wide range of responses and feeling states, among them denial, anxiety or panic, depression, anger, confusion and a spectrum of fearfulness that may range from trepidation to utter terror. The presence of dementia may also evoke shame and a concomitant desire for privacy, particularly while the impact of diagnosis is being assimilated, and so may forestall or erode any inclination to reach out for help. In these circumstances a family member or carer may act as a conduit towards the possibility of help through counselling by offering encouragement, making enquiries, easing practical obstacles and providing moral support during the process of engagement.

Third parties as facilitators

With this facilitative potential in mind, I have often found that it can be valuable for a partner or family member to be involved in part or all of the initial assessment, with the important proviso that the client is agreeable. Such a decision places much onus on the discretion of the counsellor carrying out the assessment, however in my experience this is sometimes the only way of gaining factual information which the client might otherwise struggle to remember or describe, and which can beneficially inform the work or add to its continuity once begun. The supportive involvement of someone familiar can also lend the client confidence at a time when they might feel especially sensitive about their ability to communicate with a stranger. Where an initial joint meeting does take place however, it is important to emphasise to both parties that the actual counselling will involve the client alone and that in all normal circumstances the counsellor will respect their right to confidentiality.

Because of the particular vulnerability of people with dementia it is very advisable, even in services where it is not deemed mandatory, to negotiate safeguarding contingencies as part of the counsellor's duty of care to the client. Third parties, whether or not they are present at the time of assessment, may also be in a position to notify or advise the service if serious concerns arise relating to the client's well-being which might otherwise remain unknown, and it is good practice to ask the client to nominate someone they trust in this capacity.

Family members or other services such as befriending schemes may, where appropriate, support aspects of the work which can be beneficially integrated into daily life. They may for instance do this by enabling clients to continue to participate in social situations or implement other practices that contribute to well-being, by helping to instigate memory prompts, or by encouraging the person with dementia to recognise and articulate day-to-day concerns that might otherwise remain unexpressed.

Third parties as barriers

These instances of helpful collaboration illustrate the role of the third party as a valuable and even vital facilitator. I have, however, encountered a variety of situations in which this has not been the case. In such instances, although often clearly having the best interests of the client at heart, the third party has effectively presented as an obstacle or hindrance to the possibility of the client finding meaningful help through counselling. Examples from my experience include:

- refusing the offer of counselling or

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related help on behalf of the client
- pressuring the client to make a decision about whether or not to embark on counselling
- refusing to allow the client to be seen alone
- being unwilling to assist with access where this is a necessary factor
- answering questions and/or making decisions on behalf of the client
- seeking information about the contents of counselling sessions.

No one could doubt that living with or caring for someone with dementia is likely to elicit strong feelings, and people in such a situation may act in the ways described above for a variety of understandable reasons. These might include:
- difficulty in coming to terms with the implications of a diagnosis of dementia
- feeling that their role as carer is being usurped or that they are being excluded
- perceiving professional involvement as an implied criticism of their ability to cope or to care for the person with dementia
- seeing professional support as an invasion of privacy
- believing that professional intervention will create or exacerbate difficulties, for example the person with dementia will become needlessly upset.

Sometimes fear or disinclination to permit the involvement of professionals derives from hearsay or previous experiences and may melt away in the event of a tactful and sensitive approach. It is also fair to say that the final point is indeed a genuine, if only occasional, possibility. Like all counselling work, the process of engaging in a therapeutic relationship with people with dementia is likely to have a ripple effect: its influence will probably be felt by others who are close to the person. This could usually be hoped to be experienced as positive and helpful if, for instance, counselling enables the client to feel calmer and more able to cope with or adapt to the changes that dementia brings. However, occasionally this might not be the case, for example where difficult feelings emerge which are then acted out in the home environment.

These considerations elicit the broader question of how much the counsellor should allow for contingencies involving family and/or carers in their approach to working with the individual needs of the client. Services referring people with dementia for counselling are often involved with both clients and family members/carers simultaneously. They may therefore be more likely to view the dynamics of each situation systemically, and hence, at least in ideal circumstances, adopt a coordinated approach that embraces the needs of the person with dementia and those who live with or care for them. The family members and carers I have worked with as a counsellor, or spoken to in the course of arranging counselling for people with dementia, have consistently highlighted their need for emotional support and education about the nature and potential impact of the illness. Where this is available, I suggest that attitudes such as those listed above are far less likely to prevail as obstacles to the possibility of offering counselling to the person with dementia. Because of this I feel strongly that individual counselling work can be most effective as part of a co-ordinated treatment plan which seeks to address the range of needs and challenges dementia presents to both clients and those involved in their ongoing care.

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Longer-term counselling

Dementia is commonly recognised a dynamic illness, always potentially subject to change, sometimes in ways that are sudden and unpredictable. Except in the case of Wernicke-Korsakoff's syndrome (when identified in its early stages) it is not a condition that can be reversed. By its very nature the needs that accompany the progression of a dementia will be enduring, and therefore will require more extensive support than illnesses amenable to cure or psychological conditions to healing or alleviation.

At this point in time, when funding grows ever scarcer and ever more conditional if bestowed, both the manner and necessary duration of professional support for people with dementia are at risk. Counselling work in this field, in some ways uniquely, requires a bespoke ethical and therapeutic context to provide support that is realistically attuned to the needs of the client group.

Where specialist older persons' services are being cut, subsumed into generic services, or contractually obliged to adopt ways of practicing that are at best unsympathetic and at worst totally inappropriate, it is becoming increasingly difficult to offer the particular support that older clients entering counselling so often require. Where such restrictions prevail, genuinely effective provision for clients with the additional needs that accompany dementia can, in reality, cease to exist.

Not only do people with dementia seeking counselling require specialist provision, they also need more extensive support than the 'brief' or short-term contracts that statutory funding increasingly imposes. My own experience, combined with consistent feedback from counsellors I have supervised, strongly suggests that clients with dementia need more time to adapt to and feel comfortable within a therapeutic relationship, however experienced the practitioner. Where this is the case the possibility of healing through retrospection, so often a theme with older clients, is delayed, as in consequence are psychodynamic elements in the work, which allow clients with sufficient memory the cathartic opportunity to re-evaluate salient events in their earlier lives.

Where dementia is present it also takes the counsellor more time to develop a sense of the person, to gather anecdotal information that can inform and enrich the work, and therefore to be more aware of how the dementia may be influencing the personality and presentation of the client sitting before them. For example, a failure to recognise a joke where before there would be humour, or sudden boastfulness where previously there was consistent modesty – significant changes which can only be recognised in the context of a longer relationship. There is also the not untypical scenario of the client who, after months of counselling and a lifetime of reticence and stoicism, finally discovers in their counsellor a person in whom they feel able to confide, at which point the 'real counselling' can begin.

Counselling people with dementia presents an essential dilemma: that at a time when one may naturally become more preoccupied by the past, the ability to retrieve it diminishes. In the face of such tension the desire to remember can grow more urgent, the act of remembering more significant. My impression is that people with dementia often experience a more intense relationship with times of life that remain accessible, and hence with the counsellor who facilitates retrieval and who, in the palpable act of listening intently, can effectively become a repository of the client's memories. In this respect, where significant memories might otherwise be lost or hidden in confusion, the element of dependency is unlikely to be reduced or eliminated as might be expected during generic counselling, especially as clients who face the inevitable deterioration associated with dementia are likely to grow more rather than less vulnerable during the time span in which counselling takes place.

Perhaps because of this, it must be accepted that counselling which seeks to address the needs of people with dementia will rarely allow either client or counsellor the sense of resolution that, ideally at least, can accompany work with other client groups. However, the imposition of shorter frames can inevitably make endings with dementia clients seem abrupt or inappropriate in the context of a relationship that from any ethical perspective should be allowed to conclude as naturally and with as much compassion and sensitivity as possible.

Mike Fox is the is the co-author with Lesley Wilson of Counselling older people with alcohol problems, *published by Jessica Kingsley Publishers in 2011.*

To follow up with the author about this article, contact Mike Fox on fox.wilson@virgin.net

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Inspiring staff to del

Jackie Pool describes the results of a six-month project carried out last year in 28 care homes in south east England. Its focus was to train managers and leaders to deliver high quality dementia care through the use of the Bee Inspired Dementia Care programme.

Jackie Pool is an independent occupational therapist and training consultant, and director of Jackie Pool Associates

Few would dispute that in order to achieve excellence in dementia care, a truly person-centred approach is needed, aimed at supporting people with dementia to experience the best quality of life possible. While we all know this should happen, all too often it does not. There is still incongruence between between what we know and understand (the theory) and what we do (the practice). But most care workers want to make a positive difference to the lives of the people they support and, when they do, levels of job satisfaction, morale and commitment increase.

Leadership in particular plays a crucial role in staff morale. In a review by the Residential Forum **(ref date)** , poor quality of leadership was cited as the main factor for people leaving their place of work. Most then move to other care organisations, which tells us that care workers want to continue in their caring role but are seeking more from their leaders and managers.

The Department of Health (DH)'s *Options for Excellence* report (2006) further states that a key need of care workers is to feel supported in their work by excellent leaders and managers.

The Bee Inspired Dementia Care Programme was developed by Jackie Pool Associates (JPA) in response to this need. The programme is aimed at supporting managers to lead their teams in delivering high quality dementia care. In January 2011, JPA won a tender to work with the Health and Social Care (HSC) Partnership (part of the DH regional presence in south east England) on a project to improve the lives of people with dementia living in care homes in the region.

Background to the project

One of the key reasons the project was established was to address the growing demand for care home places in the next 20 years. Newcastle University's Institute for Ageing and Health predicts an 82 per cent increase in the number of places needed between now and 2030 – a total of 630,000. As the demand for places rises, so does the need for improving the quality of care provided in care homes.

The National Dementia Strategy for England and reports from the All-Party Parliamentary Group on Dementia have both emphasised the need to improve the quality of care provided in care homes and reduce the overuse of antipsychotic medication. Another key aim of the HSC project was to deliver better dementia care by encouraging staff to consider alternatives to antipsychotic drugs, such as therapeutic interventions.

In January last year, care homes across the south east England were contacted and invited to attend a DH-funded three-day training course in central London. The Bee Inspired Dementia Care Leadership course was aimed at care home leaders or managers whose remit was to make a difference and inspire learning in their place of work. Two people from each home were invited and all 64 places available were filled in the same day the invitations were sent out. The first two days of the course ran consecutively in March. Attendees were then invited to return for a third day three months later to discuss their experiences of implementing the programme.

The main aims

The key aims of the programme were:

- to improve the awareness and understanding of dementia among the leaders and managers who participated;
- to address objectives 11 (improving care in care homes) and 13 (workforce training) of the National Dementia Strategy and to improve the quality of life of people living with dementia in care settings.

Injecting energy into care settings,