



Living Together with Dementia: A Relationship Intervention for Couples Living with Dementia

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Overview and aims of this intervention

The Living Together with Dementia intervention has been created to improve the life experience and mental health of older couples living with dementia. LTwD comprises both an intervention for couples with dementia and training for staff in that intervention. The professional training package in the LTwD approach has been designed for psychological therapists, counsellors and others, working in the mental health and social care of older people in statutory and voluntary services. The LTwD approach is unique in that it targets the person with dementia and their partner, focussing on the relationship between them. It aims to help people living with dementia to manage the trauma of the diagnosis, the loss and the changes it brings and to maintain, or recover, the protective aspects of the relationship – which research indicates are to do with emotional contact and understanding, positive interactions, shared activity and involvement and the overall quality of the relationship between the partners.

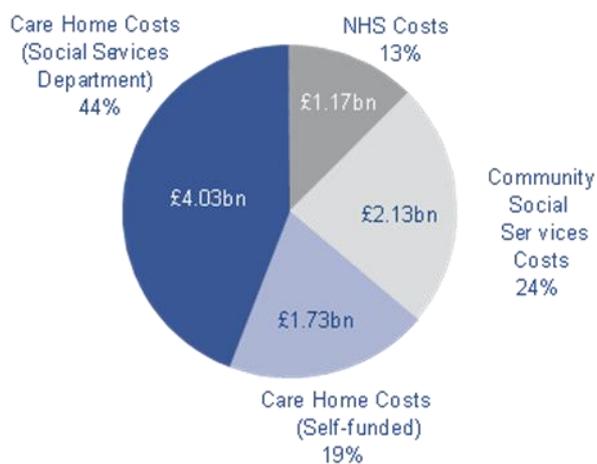
The LTwD approach offers emotional support through the trauma of diagnosis and adjustment to the illness. It aims to address negative cycles of interaction and the secondary disablement (see Figure 1 Page 6) that often accompany dementia, when people gradually lose the capacity to carry out daily activities, and become more dependent. The LTwD approach aims to enable people with dementia to continue to play an active role for longer, and to help couples to learn to adjust to the disease, and to continue with everyday activities together that support interdependence, rather than premature dependence, between the partners in the couple. For the relationship to function as a protective factor, and as a resource able to survive and to contain the care needs of the person with dementia, depends upon the resilience of the couple and on interventions that help to support this. The need for such interventions will increase exponentially over the coming years, with our ageing population and the rapidly increasing numbers of people living with dementia, currently one in 5 people over 80, and one in 20 over 65.

Policy Context and cost-benefits of TCCR's *Living Together with Dementia* Approach

Efforts in Health and Social Service policy are directed towards trying to encourage home treatment and seek to keep people in their own homes as long as possible. It is recognised that, generally home is a far better place for the person with dementia and there are obvious economic reasons also, given the cost of institutional care to public and the impact on private finances.

London's costs are higher than anywhere else in the country as the PSSRU found in their quantitative research on residential and hospital care costs for older people (PSSRU 2010), the London multiplier being a factor of 17% for private nursing care, costing on average £799.11 per week as opposed to £683 as a national non-London average. This 'London tariff' is evident in all forms of care that might be used by an older person with dementia. Local Authority costs are higher, with one week of care costing £1021.5 in London. (From the National Audit Office 2010 Dementia presentations pack)

The total estimated direct cost of dementia is £9.1 billion, the bulk of which relates to the cost of care home places



Source: Knapp et al. (2007) Dementia UKr

NOTE

£5.76 billion, equivalent to almost two thirds of the direct costs of dementia (i.e. excluding informal care costs), borne by families, the NHS and social services, relates to the provision of care home places for people with dementia. NHS costs and social services costs account for the remaining one third of direct costs.

The cost to the NHS of dementia is very high at current rates of admission, and with the projected increases in dementia, this demand presents major challenges for the NHS. Not only is care in hospital extremely expensive it is rarely a positive experience, with the person with dementia less likely to return home at the end of episode, and their stay is often longer than anticipated. In these circumstances, patients may become more confused and less able to function.

The amount of unpaid care offered by a partner or other carer in England accounts for £5.2 billion of 'savings'. It is often when a medical emergency occurs that the care becomes institutional or when the burden of "care giving" becomes too great to endure that formal care is used.

A recent report from the Institute for Public Policy Research highlights continued and worsening inequalities in older people's mental health and well-being, and points out the need for "more targeted interventions to support those most at risk of poor emotional wellbeing". The LTWd approach is such an intervention: one that will contribute to the **increased viability of home care prior to a move to residential care, if such is required.**

Historically, interventions have tended to concentrate on the position of family carers, which has overshadowed efforts to develop approaches which directly include people with dementia themselves. **Yet there is evidence to suggest that the most effective interventions are those that include both the person with dementia and their family caregiver** (Green and Koschera 2003).

The LTWd approach has the potential to be of great value to public health and patient care: to make a positive difference to the health and wellbeing of all couples affected by dementia, helping them **live independently for longer** through offering a service which delivers **effective and cost efficient support for couples living with dementia** as well as **developing the practice and training of mental health professionals.**

The Importance of the Couple Relationship in Dementia: Research Evidence

- Many governments stress the importance of early detection in their dementia policies, and in the UK this is the focus of the National Dementia Strategy (2008). As a consequence of increased awareness of the dementias in health professionals and others, and improved diagnostic procedures, we have a new cohort of people, diagnosed much earlier with dementia. With current efforts to increase early detection and diagnosis, this group will become larger.
- The experience of receiving a diagnosis of dementia is profoundly difficult, and yet there is a dearth of specialist therapeutic services set up to address the psychological impact of receiving such a diagnosis, and there is the potential for a 'care gap' (Iliffe and Manthorpe,

2004) when people are left with a diagnosis but little support during the early stages of their dementia.

- The double-stigma of old age and dementia appear to be associated with the fostering of the belief, apparent in the services across Europe, that nothing can be done in early dementia (Vernooij-Dassen et al. 2005) thus perhaps unfairly disqualifying people with dementia from rehabilitation services (Moniz-Cook and Manthorpe, 2009)
- And yet, there are now studies showing that people with dementia living at home and in care homes are capable of learning new information (Bird 2000; Camp, Bird and Cherry 2000; Clare and Woods 2001.) and that they may have 'cognitive reserve' suggesting that the brain may actively attempt to compensate for the challenge represented by damage due to dementia (Stern 2007; Moniz-Cook and Manthorpe, 2009).
- Interventions that have developed have tended to concentrate on the position of family carers and this has tended to overshadow efforts to develop approaches which directly include people with dementia themselves.
- There is no simple relationship between disease stage and the extent of the burden experienced by the spouse carer and there is evidence that the maintenance of the person with dementia in the community has more to do with the attitudes and well being of the spouse carer than factors such as severity of the disease itself.
- Where family members become distressed, few options for the continued support of the person with dementia in the home exist. One consequence of this is inappropriate and undesired admission to care homes, rather than tailored community-based services of the sort that are increasingly available for younger people with disabilities across Europe (Moniz-Cook, 2009)
- This is supported by studies that show that (i) training carers delays admission to nursing home by an average of 20 months (Brodaty, Gresham & Luscombe 1997); (ii) providing carers with emotional support delays admission to residential care by an average of 500 days (Mittelman, Hayley, Clay & Roth)
- Loss of intimacy is also associated with carer spouse depression, and low levels of interaction between the partners in the marriages of people with dementia predict the move to hospital care. One researcher (Bull, 1998) comments, "...the feeling of the loss of the partner is associated with the loss of sharing or interaction with the partner. Some carers expressed this loss of communication as: 'if only I knew what he/she was thinking'" (also Lewis, 1998; Morris, Morris & Britton, 1988; Murray, Schneider, Banerjee, & Mann, 1999).
- Emotional factors are therefore crucial – and the carer's experience of loss of intimacy and understanding of their partner with dementia has been found to be one important factor. Loss of intimacy is associated with carer spouse depression (Morris, Morris, & Britton, 1988a and Morris, Morris, & Britton, 1988b), and low levels of interaction between the partners in the marriages of people with dementia predict the move to hospital care. (Wright 1991, 1994)
- The importance of developing an intervention for couples living with dementia is illustrated by such findings, which indicate that **low levels of caregiver commitment and lack of positive interaction with their spouse predict not only moves to residential care, but also the death of the spouse with dementia two years later** Wright (1991,1994).
- **Closer relationships between carer and the person with dementia are associated with slower decline in Alzheimer's Disease, and this effect is highest for couple relationships. In other words, the closer the relationship between the partners in couples living with dementia, the slower the rate of decline in the person with AD.** The authors of this research (Norton, Piercy, Rabins, Green, Breitner & Ostbye *et al* (2009) comment that future interventions designed to enhance the care giving dyadic relationship may help slow decline in Alzheimer's Disease.

In summary

- Many people with dementia live at home with their partners and there is evidence that the quality of this relationship is of crucial importance in determining when or whether the person with dementia goes into residential or hospital care – and even how quickly they decline and die.
- Health and social care professionals, counselors, therapists and others have little or no training in how to work with such couples.
- Couples often feel stigmatised and become isolated.
- One person in the first LTWD study commented that after her husband was diagnosed she felt “...bombed by people coming in, saying you should apply for this or that...with leaflets and forms...we need one person we can build a relationship with...to help us to come to terms with what is happening” (Balfour 2014, in press).
- Often, the person with dementia withdraws prematurely with the common pattern of their partner taking over, and so exacerbating their partner’s withdrawal from engaging in everyday activities, the ‘negative loop of withdrawal’ (see fig.1).
- The partners of people with dementia have been described as ‘hidden patients’, many providing 60 or more hours per week of care.
- There are many losses facing the couple– of capacity, roles and intimacy – and the prospect of separation, with the possibility of the move to residential care. Loss of communication, understanding and intimacy are associated with carer partner depression.
- Emotional support for carers helps - delaying admission to nursing home by an average of 500 days.
- In children’s services, the child and family form the ‘unit of care’. In services for older people, individuals are treated in isolation, relationships of 60 years or more may be separated and there are no psychosocial interventions generally available to help older couples with dementia. Yet, as reported above, research shows that the closer the relationship between such couples, the slower the rate of decline in the person with dementia, whilst conversely, lack of positive interaction with their partner predict whether the person with dementia has moved to residential care, or died, two years later.

What is the ‘Living Together with Dementia’ Intervention?

The LTWD approach promotes resilience; aiming to enable the person with dementia to maintain their engagement with their partner with every day activities, finding strategies for both partners to become more interdependent; providing support and containment for both partners in coming to terms with the diagnosis, making optimal adjustment, and addressing the challenge of social isolation and the adverse mental and physical health consequences of this.

- The focus of Living Together with Dementia is upon the couple relationship itself, targeting the partner with dementia *together with* their partner. This is unique in the field of dementia care. The LTWD approach could, in future, be added to the National Institute of Clinical Excellence current dementia pathway (see summary attached page 7) where at the moment psychosocial support is directed at the carer partner separately.
- The LTWD approach is based on research and therapeutic methods developed in working with people with socio-cognitive impairments and their parents and video-based approaches used with parents and infants together with techniques from couple therapy (see below for further detail).
- It makes use of everyday family activities that are done together, such as preparing food. These are videotaped and selected interchanges played back to the couple. This helps the

couple to observe and to think about what is going on between them, and is a powerful technique in supporting change.

- The approach is structured, focusing upon techniques for greater involvement in everyday activities but is also about enabling the couple to think about and to understand their feelings.
- It is an eight session intervention, with the possibility of further follow up: an assessment, followed by six sessions and then a further session of assessment, to audit the outcome of the intervention and to re-assess the couple's needs. We have found that intermittent sessions at roughly two to three weekly intervals works well – so the initial phase of the intervention is a 'long thin' one – lasting over a four to six month plus period, with the possibility of additional follow-up.
- Further intermittent follow-up, on a four to eight week basis, depending upon the needs of the couple.

The structure and sequence of the sessions is as follows:

- Individual meetings (psychotherapeutic discussions) with each partner occur regularly throughout.
- Videotaping of new activity (week A)
- Review of video from previous session (week B)
- Alternate weeks where video new activity (week A) and week where go through video from previous session (week B)
- Each session ends with a psychotherapeutic discussion including both partners together.

LTWd draws upon relational approaches that have been shown to be effective in working with the interactions between people with autism and their parents (**the Relationship Development Intervention** Gutstein 2009). This uses techniques of close observation and videoing to study the communication and patterns of interaction between parents and children with autism, with the aim of increasing sharing and reciprocal interaction between them. We have drawn upon RDI techniques to find ways to structure increased opportunities for emotional contact between partners, using everyday activities that they do together, to counter the tendency towards withdrawal and the secondary disablement of the person with dementia.

We also make use of another approach - **Video Interaction Guidance**. This is a widely used intervention that aims to enhance communication within relationships. It is mostly used for looking at interactions between children and adults – either parents or professionals. It involves filming people in interaction together, and then selecting out significant segments to show them. The aim of this is to highlight elements that are successful and to help people to notice and think about aspects of their interaction that might be less successful and that they might wish to change. These video based approaches have been found to be very powerful in work with parents and children, helping to promote change and new understanding. For example, the depressed mother, who is convinced her child does nothing but cry is helped to see examples where he behaves rather differently, and to observe and to think about what her baby's experience might be, noticing perhaps, how the baby's behaviour links to her own, perhaps becoming more able to see moments where her baby is trying to initiate contact with her.

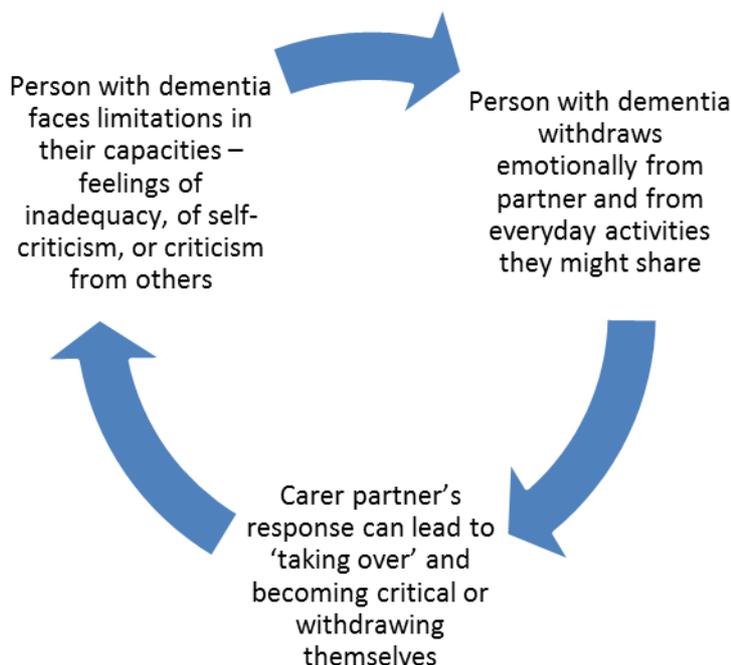
In addition, we make use of concepts and techniques from the field of **couple psychotherapy** (TCCR). The focus on the couple together is crucial. We have found that the individual partners need to be seen separately too in order to be free to say things that might otherwise be difficult to articulate in front of their partner. But this applies to both partners– and most crucially, there needs to be the opportunity for them to come together, and this is the central focus of our work. The idea is that if the couple can be helped to think about their everyday activities as opportunities for becoming more involved and mutually inter-dependent before the dementia becomes too advanced, this may

be protective and give them strategies, and understanding, that can be helpful later on. We have found the video to be a very powerful tool in helping the couple to observe what is going on between them, to get them into a different state of mind, able to stand back and to begin to question, or become interested in why things are happening between them in a particular way. The focus is upon the emotional meaning and potential of the everyday activities of life, using these in the service of creating the conditions for involvement and emotional contact – inter-dependency, between the partners, trying to hold them, for longer, in a position where they are in contact with one another – and to counteract the pressure towards withdrawal and loss of contact between the partners, which is often associated with dementia.

The LTWd approach is both structured, focusing upon techniques for enabling greater contact around everyday activities– but also is very much about trying to enable the couple to think about and process their feelings – to offer containment for their emotional state. Here, the therapeutic aim is that, if the partners are more contained, then they will need to take less recourse to defensive withdrawal – or the acting out of anger and frustration that can also be part of the picture in dementia. The activities that we video can seem mundane and every day, but being able to find new meaning and new ways of thinking precisely grounded in their daily living, is very important. Things can easily become very calcified between a couple: he or she is simply like that – with nothing to be thought about – but the video can allow something to be noticed and seen afresh in a way that is powerful, and which can support change and new ways of thinking.

LTWd uses the new generation of Flip video cameras, which are easy to use and an unobtrusive technology, which opens up new possibilities for using video in ordinary clinical settings – though clearly there are issues to consider, such as confidentiality, and safety of the recordings (we have addressed these issues very carefully, and the earlier study we did with couples was approved by the South London and Maudsley Research Ethics Committee).

Figure 1. THE NEGATIVE LOOP OF WITHDRAWAL:



LTWd intervenes to change this negative loop of withdrawal by supporting not only the carer partner, but the person with dementia AND their relationship. One very important element is in helping the carer partner to have a greater understanding of the behaviour of their partner with dementia, and the feelings underlying their behaviour.

Figure 2. Current Approaches

Currently, the partner with dementia is treated separately, and, in general, counselling and psychological support is focused on the carer-partner and not the person with dementia or their relationship.

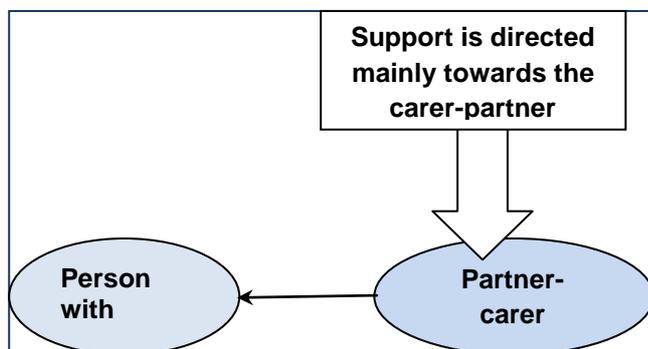
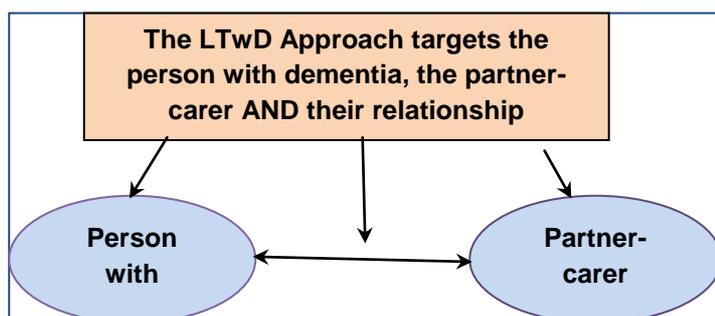


Figure 3. The LTwD Approach's proposed new Care Pathway

By focussing on helping to preserve the important relationship between the spouse carer and their partner with dementia, we aim to reduce carer stress and breakdown and to improve the life experience and mental health of both the spouse carer and their partner with dementia.



LTwD offers a manualised treatment to couples who are living with dementia. Our aim is to help to preserve the important relationship between the spouse carer and their partner with dementia, to reduce carer stress and breakdown and to improve the life experience and mental health of both the spouse carer and their partner with dementia. Critical to this work is ensuring that both partners are treated with dignity, sensitivity and respect, and that the person with dementia is included in decision making and feedback at all times.

The Living Together with Dementia Training Offer

The LTwD training model is all about capacity building. We train staff (nurses, psychologists and other health and social care workers with clinical experience of working with people with dementia) to be accredited in the LTwD approach, who are then able then to offer this service to couples on an ongoing basis, as part of the range of service provision available within their agency. In this way, the LTwD approach becomes embedded within services for people with dementia

The training comprises an initial two days' training (where we would take staff through our manual and training videos), following which the participants would then begin the clinical work within their own agency. There would then be a further follow up day, where we would determine that quality standards were being met, after which there would be ongoing supervision on a fortnightly basis. (Cases would be seen fortnightly, so there would be a lot of supervisory oversight of the casework as the participants get started.) The supervision would continue for fortnightly meetings for the period that each trainee sees two supervised cases. So overall, the training commitment would be three days plus fortnightly supervisory meetings following this – with the possibility of longer-term intermittent follow-up or 'booster' sessions. This supervision need not involve people travelling to

TCCR, it can be done via Skype and there would also be the possibility of online reviewing of participants' videos.

The approach is currently under development and, as part of the innovation process, we review learning throughout the work. Our experience suggests that we may develop the model to include long-term intermittent follow-up and keeping 'in touch' with the couples seen. Our supervisory commitment to the trainees would therefore need to reflect this, with the possibility of offering ongoing intermittent 'booster' sessions to participants. As part of the process of innovation, we need to build in some flexibility, in areas that we can anticipate, in order to include learning from our experience in our development of the model.

Piloting and Development work in Camden 2013 – 2015

Thanks to an Innovation Development Fund grant from Camden Council LTWD has undergone piloting and development work over a two year period in the London Borough of Camden. Training was offered free of charge to staff in Camden. Trainees have shown tremendous enthusiasm and commitment to carrying out this vital but at times very challenging work. Evaluation measures indicate that the trainees rate the experience consistently highly; expanding their understanding of couples with dementia, the intervention and their own sense of competence.

One participant in the Camden LTWD commented on the change in her partner with dementia:

Normally, when I bring him tea in bed he doesn't say very much, but in the last few days it is different. He's been chatting away...It's like having the old John back...he's still there after all.



Living Together with Dementia is currently operating in City and Hackney – October 2015

Living Together with Dementia is currently running in City and Hackney thanks to innovation grant funding awarded to TCCR by City and Hackney CCG.

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