

The LivDem model of post-diagnostic support for people living with dementia: Results of a survey about use and impact

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OVER the last ten years a key focus for NHS dementia services across the UK has been to make a timely, preferably early, diagnosis of dementia. The emphasis on early diagnosis enables cognitive difficulties to be addressed as close as possible to the point where they become apparent. This both maximises the person's autonomy to make decisions before their capacity is affected (Brooker et al., 2014) and enables the individual and their family to adjust to the changes occurring in their lives (Cheston, 2013; Roach et al., 2016). However, if people are to live well with dementia and to have the best chance to adjust to their illness, then good post-diagnostic support is vital. Although the provision of psychological support and access to evidence-based psychological and social interventions can help to promote adjustment, enhance mood and delay institutionalisation (Bannerjee & Wittenberg, 2009; Cheston & Ivanecka, 2017; Logsdon et al., 2010), these are often not available (Watts et al., 2014). This post-diagnostic gap is especially acute for people who receive a diagnosis of vascular dementia rather than Alzheimer's disease, or who are otherwise either not eligible for medication or do not wish to receive it, as their care is less likely to be monitored. In order to release funding for post-diagnostic care some dementia services (e.g. in Bristol and South Gloucestershire) have been redesigned so that assessment is chiefly carried out by GPs, allowing greater investment into post-diagnostic support (Dodd et al., 2014, 2016).

Research into how people living with dementia adjust to their illness consist-

ently points to this being a difficult process, involving distress, disagreement and conflict with family members, fear for the future, concerns about loss of self and identity and the experience of stress (Brooker et al., 2014; Chrisp et al., 2012; Moniz-Cook et al., 2006). To be effective, any form of post-diagnostic support should include interventions to support emotional adjustment and improve mood. There is evidence that psychological interventions including adapted forms of psychotherapy can be effective (Cheston & Ivanecka, 2017) in reducing depression and disability (Kiosses et al., 2015), anxiety (Spector et al., 2015; Stanley et al., 2013) and improving quality of life (Phung et al., 2013). Psychotherapeutic approaches can also help with adjustment (Cheston, 2013). Consequently, people living with dementia are increasingly turning to psychological therapies and counselling for support – as, for instance, Keith Oliver describes in *Dear Alzheimer's* – his autobiographical account of having dementia (Oliver, 2019).

The Living Well with Dementia course

The Living Well with Dementia, or LivDem, post-diagnostic course is an evidence-based, 10-week intervention designed for delivery within the NHS to enhance adjustment to the condition. It incorporates aspects of psychotherapeutic practice within a predominantly psychoeducational package of information giving. A UK pilot study of LivDem, in which nurses, occupational therapists and assistant psychologists were trained to deliver the course, pointed towards improvements

in quality of life and self-esteem (Marshall et al., 2014). Additionally, process analysis of transcripts from sessions suggested that at least some participants had assimilated their dementia diagnosis into their identity (Cheston et al., 2018).

Interest in the course has grown and it is currently delivered in several NHS trusts and services in Ireland and Italy. Three local service evaluations of LivDem have been carried out; all suggest that LivDem can be incorporated into clinical practice and which point to clinically relevant improvements. In Northampton, 50 participants who attended over seven sessions showed significant improvements in quality of life and well-being (Stewart et al., 2016); in Sussex improvements were found in self-esteem and caregiver burden for 38 participants across five courses. Smaller evaluations in Cornwall and Leeds (both with four clients) and Bath (with eleven participants) are all consistent with clinically meaningful improvements in self-esteem. The manual for course facilitators was published by Taylor Francis in 2019 (Cheston & Marshall, 2019) and a LivDem website will be launched in early 2020.

To find out how the LivDem course is being delivered we carried out an online survey. Ethical approval was gained and went live between June and October 2019. We invited 64 contacts who were either known to be delivering the course or had expressed an interest in delivering the course to take part. To date, twenty-eight people have completed the survey, five not currently offering a course and twenty-three reporting on their experience of delivering LivDem. In all, 10 NHS trusts provided information along with respondents from Italy and Ireland.

Who delivers LivDem? LivDem courses were generally facilitated by assistant psychologists, trainee clinical psychologists and occupational therapists. Others such as support workers, physiotherapists and psychiatric, and admiral and general nurses were also involved. In two thirds

of the groups, facilitators were working at Band 6 or below. While in five instances clinical psychologists delivered the course, their role was predominately focused around the supervision of the other staff to deliver the course.

How are facilitators trained? Thirteen said that course facilitators had attended a two-day training course; five that they had shadowed or observed a course being delivered before they started themselves; and four respondents said that their only means of training was through reading the materials.

Are LivDem courses adapted to fit local needs? Fifteen of the respondents said that they had needed to make changes to the course to deliver it within their local context. Seven said they had reduced the number of sessions. One reduced it to four sessions whilst another two reduced to eight sessions with one reporting that carers attended all sessions of their course. Course content changes included introducing more practical aids and strategies in the initial weeks. Another respondent (who had been using an earlier version of the manual) removed a section on negative thoughts and simplified the goal setting exercise.

What impact does attending the course have on participants? There was a consensus that attending the course helped people to talk about their condition, share experiences with people in a similar situation, understand more about their dementia, and to be more confident in managing their day-to-day life. Three respondents also reported that participants had increased self-esteem. Eighteen respondents reported that they had conducted their own internal evaluation of the courses. One trust reported statistically significant improvements in self-esteem and carer stress, with a second finding significant increases in quality of life and wellbeing.

Attending the course also helped people to access third-party support and resources and meant that participants developed a social network and felt less isolated. While some group members continued to meet

up informally after the formal course had finished, this was dependent on participants having access to transport.

What impact did the course have for families? This was a harder question to answer as respondents had less contact with carers than with the person living with dementia. Sixteen respondents agreed that as a result of the course many family members developed a social network and were also able to talk more openly about the dementia with their partner. Some services either currently offered a parallel course for carers in order to meet their ongoing needs or hoped that they would be able to do so in the future.

What impact did the course have for the service? Fourteen respondents said they felt facilitating the course had impacted on their service. The major change was that they were able to see first hand how people with dementia were able to come to terms with and adjust to their diagnosis. This had a positive impact on their work outside of the group setting – helping them, for example, to feel more hopeful that the person living with dementia will be able to adjust to their illness. It also helped non-psychology professionals to develop new skills that they could incorporate into their way of working.

What are the challenges in establishing LivDem? Half of the respondents ($n = 11$) reported that there had been significant challenges to delivering the course. These included practical issues such as finding appropriate and affordable venues, the lack of transport for attendees and shortages of staff to deliver it. In two areas courses had to be postponed due to staff shortages. Where respondents had not been able to deliver the course yet, they blamed this on lack of time, not having received training and not having funding. For one respondent, the biggest barrier was that the service was not commissioned to provide post-diagnostic support.

In summary, LivDem facilitators identified a range of positive impacts, both for participants living with dementia and their carers, as well as themselves as professionals.

The main challenges they face in delivering the course concerned a lack of resources, including the availability of trained staff and access to suitable venues. To address these challenges some areas have reduced the length of the course.

Discussion and conclusion

Increasingly, people living with dementia, their families and campaigning groups are highlighting the need for greater support after a diagnosis to aid adjustment (Watts et al., 2014). It is important to understand how this gap can be filled and also how people living with dementia can be supported to adjust to their diagnosis. This is not just a process of providing information, but also addressing the emotional implications of adjustment – for instance by containing the distress associated by this process.

If appropriate post-diagnostic interventions are to become more readily available in the NHS, then it is clear that this has to be done within the finite resources available and by reskilling staff. While there is always likely to be a role for specialist psychotherapeutic work, delivered by skilled therapists and psychologists, it is also important to provide a less intensive form of support that is more widely accessible. One way to do this is to provide an adapted form of support that contains elements of therapy, and which can be delivered by experienced clinicians who are not themselves trained therapists. The Living Well with Dementia course is just such an intervention.

The findings from our survey provide an indication that the basic structure of the LivDem course can be modified to meet local service constraints and needs. Additionally, there may be other innovative ways to widen the reach of such post-diagnostic interventions to make best use of distributed resources across the community. For instance, LivDem might be provided by developing collaborative working relationships with Improving Access to Psychological Therapies services (Cheston & Howells, 2016) or voluntary community sector organisations

such as the Alzheimer's Society. No matter how post-diagnostic support is provided, the need for clinical psychologists and others to engage with this area of work will only grow in future years. The LivDem course provides a practical and realistic way for the NHS to begin to provide this support.

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Tell us what you think

We are keen to learn more about how LivDem or similar forms of post-diagnostic work are

being delivered on the ground. We would welcome health professionals contacting us with their thoughts or experiences. If you would like to do this or have any other enquiry about LivDem, then please get in touch with us via email (livdem@uwe.ac.uk). A website devoted to LivDem will also become available in early 2020.

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