

FAMILY CARERS MATTER IN HARTLEPOOL

Adult Carer Quality of Life Questionnaire (AC-QoL)
Assessment Report

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In Partnership with



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FAMILY CARERS MATTER IN HARTLEPOOL!

REPORT OF THE LIFE STORY NETWORK'S TRAINING AND DEVELOPMENT PROGRAMME 2014

Introduction

The Life Story Network¹ (LSN) is a Community Interest Company based in Liverpool. We promote the use of life stories and narrative approaches to help people retain their sense of self and remain connected with their families, friends and communities. Although the approach can be used with anyone, it is particularly helpful for people living with dementia, whose impairments may make it difficult for those supporting them to get to know them and understand their past lives and present needs and wishes. Family carers may feel that they have 'lost' their loved ones, who may no longer recognise people or places in their current reality. Conversation can become frustrating and limited. Life story work provides a way of reconnecting individuals. It recognises the uniqueness of the person with dementia and their life experiences, which influence not only who they are and how they behave, but also their hopes and wishes for the future. This helps to preserve their unique identity and enable their dignity to be respected. It recognises that in order to improve the lives of those living with dementia, it is also vital to support those providing their care.

Family Carers Matter

As part of our '*Your Story Matters*' project in 2011, funded by the Department of Health, we developed a specific course with a group of family carers. It focused on practical suggestions for carers about how to respond positively to behaviours associated with dementia and introduced participants to life story work.

Feedback from participants was extremely positive. A successful bid for Skills for Care funding led to a project in Tyne and Wear to refine the course further with family carers and we have since delivered this in a number of areas including, Rochdale, Liverpool, Bolton, Trafford and Salford. The training aims not only to promote emotional wellbeing for people living with dementia, by enabling

¹ For further information about LSN visit our website at www.lifestorynetwork.org.uk

them to reconnect with earlier episodes of their lives, but also to improve relationships between the carer and the person being cared for through the shared experience of developing the life story together and providing a focus for conversations that are enjoyable and make sense to both parties. This paper describes the impacts of the *Family Carers Matter* training in Hartlepool.

Why do carers matter?

There are over 800,000 people living with dementia in the UK, with over two thirds living in local communities and most cared for at home by a relative or friend². There are 670,000 unpaid carers of people with dementia, saving the UK economy an estimated £11.6 billion. This equates to 44% of the total cost of dementia care³. Despite this, Carers UK identified that the majority of the 5,200 carers they surveyed felt they received insufficient support from health and social care services, leaving them feeling isolated, burnt-out and unable to look after their own health⁴. It is therefore unsurprising that two thirds of carers report having suffered from depression as a result of caring⁵. Research also suggests that carers of people with dementia experience greater strain and stress than carers of other older people⁶. Almost half the respondents to a recent survey of people with early onset dementia felt that their carer was not, or was only sometimes; getting the support they needed in their caring role⁷.

The consequences of carers' health breaking down is multifaceted, resulting in additional costs to the NHS, increased likelihood of more critical illness and the potential for the family member with dementia to require more intensive support, either at home or in residential care. In the current economic climate, as social care and the NHS face unprecedented demographic pressures combined with government cuts in funding, the need to improve the lives and experiences of carers of people with dementia becomes even more pressing.

The cost of ignoring or failing to recognise the significant role of unpaid carers is not only borne by the care system, further research on the importance of carers has highlighted that pressure on those

² *A Road Less Rocky- supporting carers of people with dementia* Carers Trust 2014

³ *Dementia UK: 2nd Edition - Overview* Alzheimer's Society 2014 www.alzheimers.org.uk/dementiauk accessed 241014

⁴ *Carers at Breaking Point* Carers UK 2014 www.carersuk.org.uk accessed 241014

⁵ See for example *Carers at Breaking Point* ibid; Wills, W and Soliman, A Understanding the Needs of the Family Carers with Dementia *Mental Health Review Journal* Vol 6 Iss 2 pp 25-28

⁶ *The Prime Minister's Challenge on dementia: delivering major improvements in dementia care and research by 2015* Department of Health, 2012

⁷ *Dementia 2012: a national challenge* Alzheimer's Society, 2012 www.alzheimers.org.uk/dementia2012 accessed 241014

caring for a family member with dementia is costing English businesses £1.6 billion a year⁸. This research shows that 12.1% of carers, who are employed in businesses, have had to reduce their working hours to accommodate their caring responsibilities. A further 9.2% of those under the age of 70 caring for someone with dementia have left work completely to prioritise care-giving – a total of 50,000 people. One in five businesses has had a member of staff quit their job in order to care for someone with dementia. The loss of these skills and experience from the workforce will cost English businesses £1.2 billion in 2014. It is predicted that in 2014 alone, 50,000 carers will quit their job and a further 66,000 will have to make adjustments at work. This research clearly demonstrates that businesses cannot afford to ignore the impact of dementia.

The Care Act 2014 comes in to force in April 2015 and includes a principle of **‘well-being’** as an approach that local authorities must take; it is explicit that this refers to both those with care needs and those who care for them. As Alistair Burns (National Clinical Director for Dementia) suggests, the diagnosis of dementia impacts on the whole family and therefore supporting family carers is an integral part of the care and support package for people with dementia in order for them to ‘live well’.

The Hartlepool project

Building on the success of the Skills for Care project, LSN were approached by the Hartlepool Carers Centre to deliver the training to a wider group of carers. To fund the project, we submitted a joint proposal to the Northern Rock Foundation to deliver life story work training for local family carers. The aim was to embed the necessary skills and resources within the Carers Centre to provide individual support to local carers in the future. The programme would identify a cohort of volunteers from the initial training sessions and develop their skills through further training and mentoring, to a point where they were confident they could continue to deliver this work to other carers in the community. Keeping a carer well supports the individual with dementia to continue to live independently for as long as possible while remaining connected in their own communities. The funding proposal was successful and the project, which is to run for eight months, began in March 2014.

The training, which is one part of the project, was offered to two cohorts of current and former carers and took place over two days, with an interval of approximately four weeks. 24 carers were

⁸ The Centre for Economics and Business Research (CEBR) (2014) The economic cost of dementia to English businesses - A report for the Dementia Friends Campaign -Key Findings

recruited initially but six people were unable to start the course and 12 completed both days. Some were unable to do the second day because of crises or a change of circumstances at home; of these, some are interested in keeping in touch.

Our methodology for the evaluation

We wanted to gather qualitative and quantitative information to find out if the training element was having any positive impact. We used the Adult Carer Quality of Life questionnaire (AC-QoL), published by the Princess Royal Trust for Carers⁹, which is a validated 40 item tool measuring the quality of life of adult, unpaid carers in eight domains:

- support for caring;
- caring choice;
- caring stress;
- money matters;
- personal growth;
- sense of value;
- ability to care; and
- carer satisfaction.

Participants were asked to complete this questionnaire before and after they undertook the training. They were also asked to complete a specific LSN evaluation form at the end of each day of training, which gave them the opportunity to comment on the quality of the training product and its delivery and on the benefits of the programme. Additionally, some carers took part in an interview based narrative exercise during the second day of training. These qualitative comments provided useful insights regarding the most helpful aspects of training, how the knowledge gathered from training might be used in practice and what could be adapted to improve the training received.

What we found

Reduced isolation: On average, those who attended the training felt as though their life was on hold (because of caring) 'some of the time' after the course, rather than 'a lot of the time' before the course. In particular, carers suggested that the training enabled them to do something for

⁹ Merged with Crossroads Care in 2013 to become the Carers Trust

themselves, which also benefitted the person with dementia. Similarly Carers UK found that many carers gained important emotional support and made new friends through carers' support groups¹⁰. Those who attended our training group described the benefit they got from meeting other people who were sharing similar experiences, enabling them to feel less isolated. One carer reported that "it made me feel less alone". For this reason, many hoped that the peer support they had received from other carers over the two days of training would continue in the future, possibly through the use of on-line forums, follow-up sessions or regular meetings. A number of attendees suggested that they would like to remain engaged with life story work and in particular the Life Story Network e.g. by delivering future training. It was suggested that this would not only help other individuals caring for someone with dementia, but would also give themselves purpose and a feeling of empowerment.

Satisfaction with their caring role: Attendees felt *satisfied with their life as a carer 'a lot of time'* following the training, rather than *'some of the time'* beforehand. In particular, participants reported that they now found spending time with their loved one *"a pleasure rather than a chore"*. By sharing experiences and ideas with other carers, it enabled many to see their caring role with a "fresh pair of eyes". Developing an understanding of the benefits of life story work also enabled carers to identify what *they* wanted to gain from the carer relationship: *"It has made me realise the things I want to find out about my mum's life before it's too late"*. It is likely that this enabled carers to acknowledge the *relationship* between themselves and their loved one, rather than identifying themselves solely as a 'carer'.

Sharing skills: A number of attendees acknowledged that the training provided them with new ideas and strategies to try when caring for their loved ones. They gained this not just from the specific training delivered, but also from sharing ideas with other carers. One carer identified that: *"I've got new things I can try with mum but I was also able to suggest a few things to other people"*. Some identified that they would enjoy and benefit from completing their own life stories: *"I thought I was too young but maybe I should start doing my life story too, start writing things down"*. In this way, they would be able to contribute to their life stories providing a clear account of their own lives and what was important to them.

Reduced frustration: Carers UK identified that alongside feelings of love and duty, carers report feeling trapped, desperate and often frustrated by those for whom they care¹¹. Participants in our training suggested that it helped them to understand that some of the more challenging behaviours

¹⁰ *State of Caring 2014* Carers UK, 2014

¹¹ *Carers at Breaking Point* Carers UK 2014

exhibited by those with dementia are not intentional or wilful. In particular, finding new ways of communicating reduced carers' frustrations and improved their tolerance of their loved ones' behaviour. One carer said they would try to *"approach my mother in a different way"* rather than become frustrated by the difficulties of talking to her. Additionally, carers identified that communicating with their loved ones was not about *talking at them*, but rather, *being with them*. One carer stated: *"I struggled to communicate with mam. I always felt I had to bombard her with questions but I've realised that was a waste of time"*. Instead, she intended to *"encourage mam to talk about her memories and not correct her...to let her tell me what she wants to tell me"*.

The value of life story work: Participants were keen to *"spread the word"* about the benefits of life story work so that it could be implemented elsewhere. In particular, carers wanted to encourage care homes to utilise life story work so that it could be used with other residents. It was recognised that professional carers might also become less frustrated with residents with dementia if they had a better understanding and knowledge of those individuals. In order for this to be possible, it was felt that *"care home staff should be trained on all aspects of life story work"*. Additionally, carers suggested they would encourage other family members to get involved. One carer stated that *"I want the rest of my family to understand through life story what mum and dad are all about"*. The majority of attendees felt that engaging in life story work would be 'valuable' or 'very valuable' to their friends and family. They believed that better family involvement would help to maintain and encourage relationships that may have become strained or where contact had reduced. This was particularly evident with grandchildren: *"I'm hoping to get the grandchildren involved. I'll ask them to write memories of granddad and maybe they'll be more willing to go and see him"*.

More enjoyment from being a carer: By improving communication and identifying new ideas and strategies, attendees described how relationships with loved ones had improved, as had the experience of caring. One carer explained that *"it's nice to go home and think it was a better visit today and go home with a smile...it was a pleasure to see her, we've found each other again"*. Overall, of all the aspects of carer quality of life that were measured for those who attended the training course, carer satisfaction appeared to improve most. All but one aspect of carer satisfaction improved in some way over the two days. The importance of this was identified by one carer as they suggested that *"if carers feel good they can help the person more"*. This confirms research findings that by providing better support for unpaid carers, the lives of those with dementia being cared for will subsequently improve.

Other benefits: The findings show that, generally, those who attended the training felt that they now **had more control over their own lives** and were **better able to save for a rainy day**.

Unforeseen consequences of the training

We were surprised to find that participants reported after the training that they felt “*less able to get the help and information they needed*”. However, it is possible that undertaking the training raised carers’ awareness and enabled them to identify gaps in the help and information they had previously been offered. This may have encouraged carers to think about the types of support they would find beneficial and to acknowledge that these had not previously been made available to them, either from professionals or other family members. In line with this, it was identified that carers would like the opportunity to bring their family members together in order to communicate their feelings and explain some of the challenges they were facing. Carers UK have highlighted how changing family structures mean that local support networks of extended family are increasingly rare and carers are unlikely to be able to rely on this kind of help¹². This is therefore clearly an area of carer support that needs addressing.

Lessons for the future

The training element of this work has confirmed its value for family carers, i.e. introducing life story work as a way of improving communication with and understanding of the persons being cared for can refresh and restore positive and fulfilling relationships. Although a small programme, the training evaluation points the way to developing constructive ways of working with family carers that improve not only their own sense of agency and well-being but have positive benefits for the people with dementia they are caring for. Health and social care services are under severe pressure, resulting in their resources being targeted at people with the most intensive support needs; even then, there are few resources aimed specifically at supporting family carers in their own right. Care home staff may have little capacity to spend time with individual residents beyond providing personal care. In these circumstances, improving the ability and confidence of family carers to continue providing support and building community capacity through volunteering are essential components in sustaining individualised care and support. Empowering family carers with more knowledge & confidence enables them to influence the care being provided by professional staff and become a true partner in care when the person moves in to residential care or is admitted to hospital.

¹² *Carers at Breaking Point* Carers UK 2014

However, the course confirmed that it can be difficult for carers to participate, even in planned events, because the needs of the person they are caring for change or they are unable to get the expected support to 'free them up' for a few hours.

In order to achieve sustainability, the next phase of the project involves recruiting volunteers from the training group to undertake further training and help other carers benefit from the same courses. Five of the 12 have come forward and are now undergoing an induction into this aspect of the work. The new National Carers Involvement Network, to be launched in March 2015 and hosted by the LSN, will provide further support and resources and give a stronger voice to family carers of people living with dementia.

Family Carers Matter is an important contribution to the learning about the value of life story work and individual reminiscence therapy for people with dementia and for their carers; using a life story book, photo album or memory box with the individual with dementia can be an enjoyable activity for all parties and the familiar contents can have a reassuring and calming effect. In their systematic review, Subramaniam and Woods (2012) pointed out that research into reminiscence work has not kept pace with advances in practice, but concluded that *'there is now a small body of evidence suggesting that carrying out a life review with a person with dementia, culminating in the production of a life story book, is associated with improvements in cognition and well-being'*¹³. Our project suggests that there are also significantly important benefits for carers too.

¹³ Subramaniam, P and Woods, R The Impact of individual reminiscence therapy for people with dementia: a systematic review *Expert Review of Neurotherapeutics* May 2012, Vol. 12, No. 5, Pages 545-555 www.informahealthcare.com/doi/abs/10.1586/ern.12.35 accessed 241014



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