



LIVING WELL AND ENHANCING ACTIVE LIFE: THE IDEAL STUDY



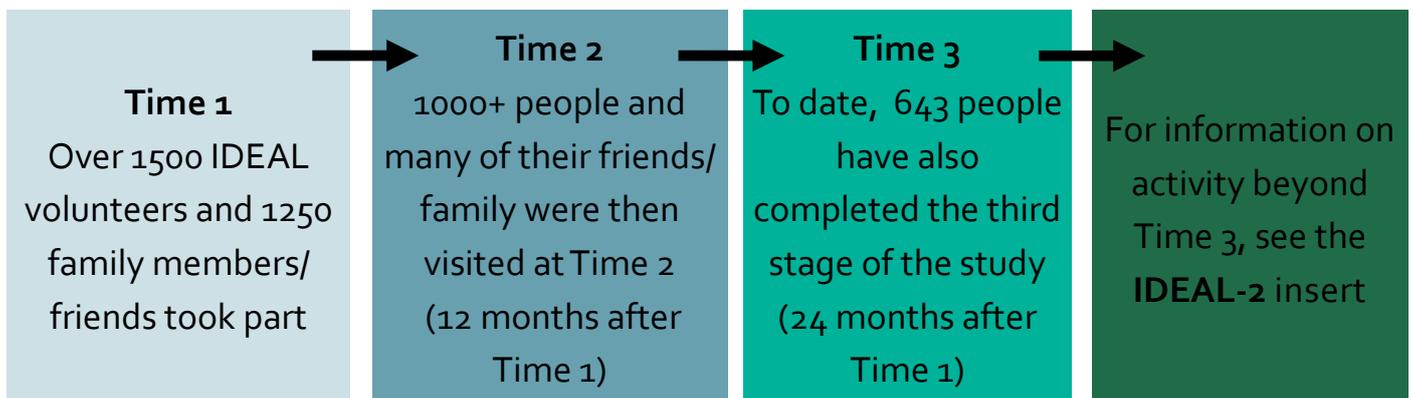
Welcome to the IDEAL Study newsletter.

We are sending you this newsletter because you have taken part in the IDEAL study and have given us your permission to contact you.

For more information go to: www.idealproject.org.uk

You can also follow us on twitter  @IDEALStudyTweet

IDEAL Update



The research team have begun to use the information from Time 1. They are looking at factors that help those affected by dementia to live well.

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Recent IDEAL Activities

IDEAL event 'Dementia: Personal experiences and cultural representations'

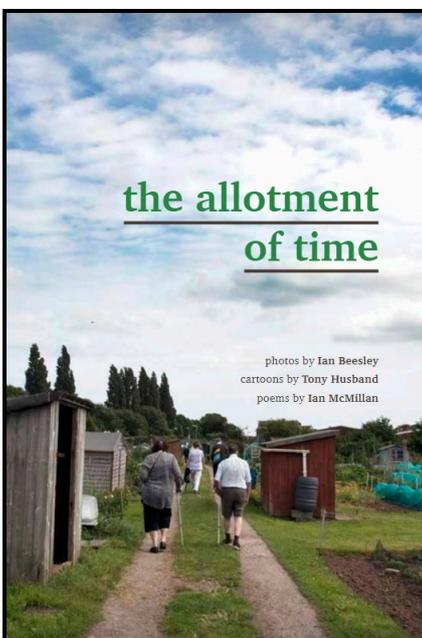
In November, the IDEAL team ran a free public event at Exeter Phoenix's 'Studio 74'. This was part of the Economic and Social Research Council's 'Festival of Social Science'. The event aimed to get people thinking about how we view and discuss dementia, and how this might affect those living with it.



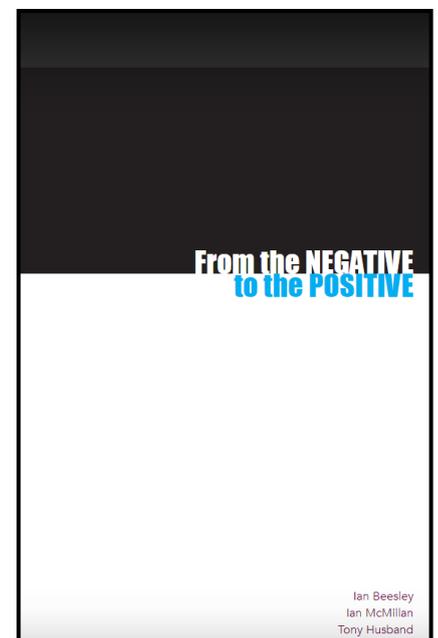
Keith Oliver - author of *Walk the Walk*, *Talk the Talk* - opened by sharing his thoughts on living with Alzheimer's disease, being an advocate for those with dementia and the important role he plays in dementia research. Researchers Dr Alex Hillman and Dr Catherine Quinn, and Steve Milton from 'Innovations in Dementia' all then spoke (pictured above). They led discussion around how dementia is portrayed in culture (e.g., through film, TV, newspapers) and the importance of the terminology we use. Thank you to all who attended.

IDEAL artist's workshops: 'Chapbooks' published

Linked to the IDEAL study, Ian Beesley (photographer), Tony Husband (cartoonist) and Ian McMillan (poet) have joined forces to work alongside groups of people affected by dementia for the 'A Life More Ordinary Project'. So far two 'chapbooks' (small booklets) have been created by the artists and groups in Exeter and Oldham. The artists illustrate some of the day-to-day experiences of the groups through photography, poetry and cartoons. The chapbooks have been featured on local radio, TV and in the magazine *Nursing Older People*.



The chapbooks are freely available to download online at <http://www.idealproject.org.uk/almo/chapbooks/>



Living Well and the Power of Sharing Experiences

*In the last IDEAL study newsletter, Dr Alex Hillman discussed the potential benefits of individuals sharing their experiences of living with dementia with others. Following on from this, **Margaret Gordon** (IDEAL study volunteer) has kindly agreed to contribute to this issue, sharing some of her reflections.*

My husband of 55 years was diagnosed with Alzheimer's Disease three years ago. We had always lived an active life, individually and together, so were determined not to let this change things for us – living with dementia had to mean living well with dementia. We knew it was not going to go away but set out to treat it as the next stage in our lives. Being diagnosed at an early stage of-course was an advantage.



The first challenge for both of us was holding on to the things we liked best in life and letting go of some others. Having done voluntary work on the committee of our local RDA for about 12 years, giving up that was a wrench for Alan but necessary. Similarly my active part in our local East Lothian U3A had to be curtailed. But with good friends, Alan was able to continue most of his interests – walking, golfing, swimming and going to the gym, always making sure that all the friends and acquaintances he came in contact with knew that he had Alzheimer's. In fact to begin with he used to get a bit put out at the golf club because although many of his friends had various age related ailments and got lots of sympathy, all he got when he said he had memory problems was – 'Oh we all have those'!

We volunteered to help research hoping we could learn more about our situation and hopefully help others in some way. We (I more than Alan) started reading, watching, listening, searching online to learn more but also to find out what was available to help us make the best life we could, looking for things we could do together that we could enjoy and get satisfaction from.

We received piles of literature about what help was available in our local area but that was not what we needed at that early stage. We needed human, face to face contacts. We were invited to a memory course at our local psychiatric hospital and here learned a wonderful lesson – namely, that we were not alone!! Being able to share experiences with others was the best thing that came from that, the encouragement we needed.

From that first memory course we heard by chance about a voluntary initiative called 'Lets Sing' – set-up by a former employee of Alzheimer's Scotland and led by a wonderful Community Musician, Penny Stone. Using no instruments she has us singing in 2, 3 and 4 parts, or rounds – anything from Chattanooga Choo Choo to Pachelbel Canon with wonderful folk songs from all over the world. Alan has always enjoyed music—he still goes to a Folk Group of the U3A and a Jazz Appreciation group—but our weekly choir is something special. In Alan's words 'I like the team spirit that Penny instils which helps make us disciplined but appreciative. She stretches our brains.'

Now, having made friends there that we both can relate to, we have learned of many dementia friendly initiatives in and around Edinburgh with focused interest. Our Galleries, Museums and National Library offer 'dementia friendly social events' specializing in what they each have to offer. Our theatres do similar things. We are still discovering them. Life goes on.

Caring and Working

PhD researcher, Rachel Clarke has been doing interviews with a number of people caring for a loved one with dementia at the same time as doing paid work. She has interviewed fifteen adult children, one grandchild and eight partners of those with a diagnosis of dementia. Early findings highlight some factors that are important for individuals in this setting.

Rachel found that aids to organisation were important (i.e. smart phones and tablets). One interviewee stated: *'I love my tablet, it goes everywhere with me....my tablet has enabled me to synchronise...my work diary with my diary that I share with my [spouse] which enables me to achieve the ridiculous list of things I'm supposed to achieve, because I kept double booking myself....with the caring commitments'*.

The support of others was another important factor which enabled individuals to balance



both roles. One interviewee talked about the way in which other members of the family support the caring process: *'My [spouse] in particular. [They're] very helpful if I've got appointments I need to attend. [They] can stay with my mother'*.

Successful examples of work, caring and life balance came from carers who were well supported by care services and within the workplace. One carer told us: *'I'm really impressed with the support outside of work. I mean we've been quite amazed... work is very good... my colleagues, my Manager'*. For some working carers, employment was described as a respite from the care role: *'having a job erm....is, is one of the things that kinda takes my mind away from the caring responsibilities'*.

Rachel's work highlights both some of the important strategies people use, but also many of the challenges people face when both caring for a loved one and working. She hopes to publish more of her findings in the near future.

Rachel Clarke is funded by the Economic and Social Research Council and based at the University of Sussex.

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