



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 IDEAL research project is a major, five-year study taking place across Great Britain.

Since we started in 2014, over 1500 IDEAL volunteers and 1250 family members or friends have taken part in the first stage of the study.

Over 1000 people have already continued to the second stage of the study (12 months after their initial involvement). Over 300 people have also completed the third stage so far (24 months after their initial involvement).

We will use the information we have gathered to look at factors that are important for someone to live well.

The project team are busy analysing the information collected and future newsletters will keep you informed about our findings.

We would like to share some of the work we have been doing in this newsletter: including an extension to the study following success in applying for additional funding, some activities and events we have organised, and some linked research work we have conducted.

We hope you find this of interest.

IDEAL Study Receives Funding to Continue

We are delighted to tell you that we have been awarded an Alzheimer's Society programme grant to continue the IDEAL study.

The new study will be called 'IDEAL-2' and we will be an 'Alzheimer's Society Centre of Excellence.' It will start on 1st January 2018 and last for 5 years. We will provide you with more information about IDEAL-2 closer to the start date.

On behalf of the IDEAL study team pictured we would all like to say a big thank you to the volunteers that have made IDEAL possible. We hope you will take this opportunity to continue your valuable input into the project with the new study IDEAL-2.



Living Well with Dementia : A Review

A key aim of the IDEAL project is to find out what enables an individual to achieve a good quality of life while living with dementia.

To make sure we do this as comprehensively as possible IDEAL researchers carried out a review of previous research in this area. The review draws together information from 213 studies from all over the world. It looks at which aspects of everyday life most strongly relate to the quality of life of people living with dementia.

As you might expect, many different factors are important for a good quality of life.

In particular, the review highlighted the importance of having good relationships with family and friends, feeling healthy, and not feeling anxious or depressed. Going out with family and friends, and carrying out everyday tasks (such as shopping, household tasks and engaging in skilled activities) are also important.

Once published this review will contribute to our understanding of factors that shape quality of life and direct our focus the IDEAL study results.

Recent Activities

As a project team we have been busy presenting findings from our review and interview work at conferences and events including:

- * The British Psychological Society Conference
- * The British Society of Gerontology Conference
- * Devon Partnership Trust Research Conference
- * Bangor Emerging Researchers in Aging Event
- * National Assembly for Wales
- * Bristol Dementia Service Development Day
- * South West Church Leaders Dementia Study Day

In addition to these activities, IDEAL researchers ran a number of events for Dementia Awareness Week 2017 in London and Cardiff.

The Power of Sharing Experiences: IDEAL Interviews

Before embarking on detailed interviews with a number of the IDEAL study volunteers, Dr Alex Hillman has trialled her interview approach with a small group of people with dementia and a family member or friend.

Unlike the structured questionnaires used in the main IDEAL study, these interviews are more like a guided conversation and allow people to describe their experience of living with dementia in their own terms. As well as informing our approach to future interviews, these test interviews have provided interesting insights in their own right.

Benefits for the individual...

The interviews highlighted the significance and implications of sharing stories about what it is like to live with dementia.

One man described his experience of telling his story to his local church congregation:

'[I was] asked to speak to the congregation about living well with dementia because there were people in the audience, he [the vicar] felt, who would benefit from hearing it. And that was good, that was worthwhile.'

Organising and sharing our personal stories provides a way of making sense of any changes.

Acknowledging symptoms of dementia can be challenging for an individual, but may also be beneficial by enabling an individual to hold on to the important aspects of what makes them who they are.

Benefits for others...

Stories also play an important role beyond the individual story teller. Sharing and re-telling stories about what it is like to live with dementia is an important way of challenging misperceptions and prevalent stigma surrounding a dementia diagnosis.

This power of telling stories was recognised by the participants themselves, like Jane (not her real name) who told us:

'I do it (telling her story) because I want people to understand.'

Informing future support...

The test interviews showed much diversity in the experiences of those with a diagnosis of dementia, but also highlighted shared and connected experiences.

These stories can create, enable and facilitate a more informed approach to living alongside people with dementia and provide guidance on the kinds of services and support that might enable individuals to live well with a diagnosis.

Now the test interviews have been completed, 20 IDEAL study volunteers will be invited to take part in the actual interviews in the coming months.

Sharing Experiences through Photographs, Cartoons and Poetry

Ian Beesley (photographer), Tony Husband (cartoonist) and Ian McMillan (poet) visited Kent in May as part of the 'A Life More Ordinary' project linked to IDEAL.

The workshops in Canterbury and Maidstone produced both amusing and thought provoking visual and poetic representations of living with dementia.

Some examples of these can be seen on this page.

The workshops explored the themes of routine and the now.



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'Routine, Routine, Routine'

Poem by Ian McMillan

He is washing again

What should I do?

Every day the same

Easy to forget

Do rabbits have routine?

Laughter is part of me everyday
routine

Routine, routine, routine

I go to the cathedral

Wash the floor, close that door

Routine takes the space of dreams
and possibilities

I get side tracked easily

Routine is very important

I should read that article

Arrgggh! Scream, shout, and go out

Where is everyone in my
expectations?

And whether I can park close enough
to get home

I struggle to keep to the list

The school run determines how much
freedom I have

My alerts on snooze, lead to
forgetting my tablets, as other things
are now present

Checking the clock once more

It seems that I will be OK

Get up clean your teeth and then
what

Every day is different

Sometimes routine can be very boring

Think about lovely things

I have to stop, sit and rest

Is it help or a hindrance? tick tock