

Design Challenge: Living well with dementia

Supplementary information report



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1.0 Introduction

1.1 The challenge

Until recently, dementia was something that did not get talked about. It's only in recent years that major work by campaigners, charities and researchers has made people sit up and listen. Now the government has a national dementia strategy. Now we have spokespeople like Terry Pratchett, who is living with dementia but continues to eloquently campaign for better public understanding of its effect on individuals and families. And this spring a major UK supermarket made the Alzheimer's Society and Alzheimer Scotland its charity of the year. Finally, dementia seems to be under a national spotlight.

But this spotlight has revealed the sheer scale of the challenge now facing us.

There are currently around 750,000 people living with dementia in the UK. These numbers are predicted to rise dramatically – more than doubling by 2051.¹ The simple explanation is that people are living longer; as more people live beyond 65, growing numbers will be living with dementia. One in three of us who live to 65 will have some form of dementia before we die.²

The economic and social costs of dementia are enormous. The UK currently spends around £20 billion per year on dementia – by 2026 this will have risen to £35 billion. Meanwhile, there are no calculations that can put the countless human stories into perspective. Dementia eventually affects every aspect of a person's life, and the lives of those caring for them.

But having dementia doesn't mean immediately losing your independence or quality of life. Many people continue to live well with dementia for a considerable period of time. When it comes to quality of life and wellbeing, people with dementia have many of the same expectations as people without it. Reasonable health, good relationships, financial security, hobbies and interests, and as much independence as possible – these are things we all want. As more people are diagnosed earlier, we will see growing numbers of people living with dementia whose expectations and aspirations are completely at odds with how dementia is conceived in the popular imagination.

This is where the challenge lies. To have a good quality of life and live independently, people with dementia and their carers need the right support. But currently there are major gaps in the support available to help people with dementia live life to the full. Examples of truly innovative services in this area are few and far between.

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¹ Alzheimer's Society, Dementia UK 2010 projections, http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=412 (last accessed 27 July 2011).

² 'Experts predict dementia epidemic', *BBC* News, 4 June 2007, http://news.bbc.co.uk/1/hi/scotland/glasgow and west/6718127.stm (last accessed 27 July 2011).

This is where the Design Council's *Living well with dementia* challenge comes in. It's about finding new ways to help people with dementia and their carers to live well.

How to use this document

This document does several things:

- It provides key information about dementia in the UK, including its prevalence, costs, and the ways it affects individuals and communities.
- It looks at how the current system of dementia care works and discusses some of the main problems that are preventing it from providing people with dementia and carers with the support that they deserve.
- It illustrates what living with dementia is like both for the individual and those looking after them.
- It highlights barriers to living well, and suggests areas that could be improved.
- It provides examples of good practice, as well as relevant innovations in other areas which might prove inspirational.

This document was written to inform and inspire those interested in the Design Council challenge. It does not provide exhaustive coverage of the topic; but it should get you thinking and will help you understand the key issues with dementia.

This report was independently commissioned by the Design Council from Chris Cox and Ruth Flood. Any views and opinions expressed are those of the researchers or the original source and are not those of the Design Council or the Department of Health.

2.0 What is dementia?

2.1 An introduction to dementia

While dementia has become more widely recognised in recent years, the nature of the condition is not generally understood. This section gives an introduction to dementia – what it is, and how it affects people.

The term 'dementia' describes a set of symptoms which result from various brain illnesses. By far the most common is Alzheimer's disease, which accounts for around two-thirds of dementia cases.³ Other common dementias include vascular dementia, fronto-temporal dementia, and dementia with Lewy bodies. These diseases affect the brain in different ways and produce varying symptoms.

Dementia is progressive, which means the symptoms become more severe over time. However, people with a dementia diagnosis can live a long time. For example, people with Alzheimer's live an average of eight years, though some may survive up to 20 years.⁴

The way that each person experiences dementia is unique. It will depend on many factors, including which underlying disease they have, but also their general health, emotional resilience and support network. Nevertheless, symptoms typically include:

- Loss of memory for example, forgetting the way home from the shops, or being unable to remember names and places.
- Mood changes these happen particularly when the parts of the brain, which control emotion, are affected by disease. People with dementia may feel sad, angry or frightened as a result.
- Communication problems a decline in the ability to talk, read and write.

Individuals may also develop behavioural and psychological problems such as depression, psychosis, aggression and wandering. ⁵ These can be very upsetting for the person, and make caring for them very challenging.

The symptoms of dementia can seem alien and confusing, so it helps to understand what is actually happening to the brain. The Alzheimer's Society has an excellent video tour of the brain, which shows the different stages of the main diseases that cause dementia. It can be watched here: http://alzheimers.org.uk/braintour

³ Alzheimer's Society, 'Dementia UK: The full report'

⁴ Alzheimer's Association, 'Brain Tour', http://www.alz.org/brain/13.asp (last accessed 27 July 2011).

⁵ Department of Health, 'Living Well With Dementia: a National Dementia Strategy'

Disease progression varies considerably, but broadly falls into three phases⁶

Early stage symptoms, often misattributed to stress, bereavement or normal ageing include:

- Loss of short-term memory;
- Confusion, poor judgment, unwillingness to make decisions
- Anxiety, agitation or distress over perceived changes and inability to manage everyday tasks

Middle stage symptoms include:

- More support required, including reminders to eat, wash, dress and use the lavatory
- Increasingly forgetful and may fail to recognise people
- Distress, aggression and anger are not uncommon, perhaps due to frustration
- Risks include wandering and getting lost, leaving taps running or forgetting to light the gas
- May behave inappropriately e.g. leaving the house in night clothes
- May experience hallucinations

Late stage symptoms include:

- Inability to recognize familiar objects, surroundings or people but there may be some flashes of recognition
- Increasing physical frailty, may start to shuffle or walk unsteadily eventually becoming confined to bed or a wheelchair
- Difficulty eating and sometimes swallowing, weight loss, incontinence and gradual loss of speech

Here are some online resources which give an introduction to dementia:

- 'What is dementia?' Alzheimer's Society fact sheet: http://alzheimers.org.uk/site/scripts/documents info.php?documentID=106
- Terry Pratchett on Alzheimer's Disease (video):
 - Part 1: http://www.youtube.com/watch?v=Z44ip5kYQ8w
 - Part 2: http://www.youtube.com/watch?v=NTPdubbQISQ&feature=related
- University of California Television: Lecture introducing Alzheimer's Disease (video):
 - http://www.youtube.com/watch?v=FRFRuTUAfro&feature=related

⁶ National Audit Office, 'Improving Services and support for people with dementia.'

2.2 Who is affected by dementia?

Anyone can develop dementia. While there are some measures that can help prevent or delay onset – exercising and living a healthy lifestyle, for instance – we could all find ourselves living with it. One in three of us who live to 65 will have some form of dementia before we die. ⁷

Dementia primarily affects older people. (Dementia which appears before the age of 65 is called 'early-onset'; after 65 it is called 'late-onset'.) One in 20 people over 65 have a form of dementia — one fifth of people over 80 do.8 But younger people can also get dementia. There are over 16,000 people in the UK under 65 who have dementia, though as this number is only based on referrals to services, experts say the real figure could be up to three times higher.

There are more cases of early-onset dementia in black and minority ethnic (BME) communities, reflecting their younger age profile. It's estimated there are about 11,000 people from BME groups with dementia. ⁹

2.3 How does dementia affect a person's life?

'I spoke with a fellow sufferer recently (or as I prefer to say 'a person who is thoroughly annoyed with the fact that they have dementia') who talked in the tones of a university lecturer and in every respect was quite capable of taking part in an animated conversation. Nevertheless he could not see the teacup in front of him. His eyes knew that the cup was there; his brain was not passing along the information. This disease slips you away a little bit at a time and lets you watch it happen.' Terry Pratchett ¹⁰

Living with dementia means coping with the progressive loss of physical and mental abilities. It can have a profoundly negative impact on the individual and those around them, gradually transforming every part of life until the person becomes completely dependent on either their loved ones, paid carers, or some combination of the two.

Dementia can affect the person in many different ways. They may no longer have the attention span or ability to concentrate on activities they used to do. They may not be allowed to drive. Going on holiday becomes challenging, they may have to stop going on holiday altogether. There are many emotions to deal with: frustration and short-temperedness, depression and anxiety, confusion and fear. No longer being able to deal with domestic finances and other daily tasks can be disempowering.

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⁷ 'Experts predict dementia epidemic', *BBC* News, 4 June 2007, http://news.bbc.co.uk/1/hi/scotland/glasgow and west/6718127.stm

⁸ Alzheimer's Society, 'Dementia UK: The full report'

⁹ Alzheimer's Society, 'Dementia UK: The full report.'

¹⁰ Alzheimer's Society, 'Out of the Shadows'

The sting of stigma and lost friends can dramatically impact on people's confidence and wellbeing. They may not want to disclose their diagnosis to people.¹¹ And all of this becomes more, not less, challenging as time goes on.

For insights into what living with dementia can be like, the following resources are useful:

- 'Out of the Shadows: Living with dementia' (video): http://www.youtube.com/watch?v=WR74FEyc9KY
- 'Going Home: A Short Film on Dementia' (video): http://www.youtube.com/watch?v=9iXPHhfk 7E
- 'Losing Myself' (video):
 http://www.dementiaworks.co.uk/losingmyself
- 'A Day in the Life of an Alzheimer's Sufferer' (blog): http://www.healthcentral.com/alzheimers/day-in-the-life.html
- 'Living with dementia' (Alzheimer's Society resources and information): http://alzheimers.org.uk/site/scripts/documents.php?categoryID=200342

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¹¹ Alzheimer's Society, 'Out of the Shadows'

Insert 1: People living with dementia: Ann Johnson and Christopher Devas¹²

People living with dementia

Ann Johnson and Christopher Devas both have Alzheimer's disease and gave presentations about life with dementia at the UK Dementia Congress in Bournemouth in November. Here are extracts from their speeches:

Ann Johnson

I was diagnosed with Alzheimer's disease five years ago when I was 52. I am now 57. This is not a nice disease to have. A big problem I have is short term memory, but there are other things tied up with it.

Taking my medication, Aricept, means everything to me. When I started taking it I became alert again. Before that, it was like living in a mist and a fog all the time.

My specific problems are a little difficult to explain because you can't see them. I have great difficulty remembering things, working things out and interpreting things. I use a Dictaphone which helps considerably. I can't use a normal watch so I've gone digital, but that has its limitations. I can't read very well so I use audio books. I can't count money, but I haven't found a way around that yet so any suggestions will be gratefully received!

So, I've developed strategies to help. These can be very simple but effective if they work. Often it is the simplest things that get the better of us - things we have done all our lives without a problem. But now, because we can't do them, it is very frustrating.

Frustration itself can lead to problems. It may evoke a change in behaviour which we may be unaware of. When frustration gets to me, I am not a nice person to know, but I would rather be told if my behaviour is unacceptable as I may not be aware.

Sometimes I feel useless and rubbish, and that is when the tears start. The realisation that you are losing your abilities is difficult to come to terms with. I am a trained nurse and was a lecturer in nursing so it is difficult for me when I can see myself disappearing.

Although medication helps to keep things stable, when I see changes happening to me and things getting worse, it is difficult to handle. I often wish I hadn't got insight.

I find myself in a life-changing situation, but I give thanks for the things I can still do rather than moan about what I've lost. I was asked at a talk what keeps me going. I said my friends, my faith and doing talks. Without any one of these I would be sunk.

¹² Dementia UK, www.dementiauk.org.

Christopher Devas

I am 66 years old and was diagnosed with Alzheimer's disease two years ago. I prefer to call my dementia 'Altz.' She has come to live with me without asking!

Prior to 2008 I didn't realise that Alzheimer's disease was invading my life. At the time I wasn't sure what was wrong. I wasn't quite on top of things at work or at home. My doctor referred me to a specialist. I was diagnosed and prescribed Aricept which has, I think, kept me on a plateau, although I don't know where I would now be without the pills. It was very reassuring to know that I was being helped. Early diagnosis is the key. I told my friends and family that I had Alzheimer's disease, so they wouldn't be embarrassed if I was struggling to find a word or two.

After my diagnosis, we rang Alzheimer's Society in Dorset and they gave us all the avenues to go down. Through attending the Memory Café, we met the Community Mental Health Team, which is wonderful and a great support.

From then on, it was a matter of finding things that would be useful. Often, an idea or thought would come into my head which I knew I'd forget. I now have a little dictating machine which I take everywhere.

My phone, dictating machine, biro, money, car and door keys now all have a place to 'live' so that when I go out, I know where to find them. I find reciting the alphabet slowly is a good way to find the name you are looking for.

Having a wife who doesn't mind how weird my shopping is or that her drink has been put in the fridge is a great comfort.

I would like to say to other people who have problems with their memory to try not to be afraid to face your Alzheimer's disease, and try not to let it get you down. I find that a positive attitude is essential!

You could try something new. I went to Singing for the Brain and have now joined a choir. They told me at school I couldn't sing. This time I haven't asked anybody!

For the last two years I have been able to help a friend on a part-time basis to deliver parcels, which has been a huge help and good fun.

If you know somebody that you think might have Alzheimer's, please persuade them to go to their GP. It is most important that people have an early diagnosis so they then can move on.

I would like to finish with a quote from the book, Still Alice, by Lisa Genova: 'My yesterdays are disappearing and my tomorrows are uncertain, so what do I live for? I live for each day, I live in the moment.'

3.0 The challenge of dementia in the UK

3.1 What are the costs of dementia?

On a national level, every dementia patient costs the economy £27,647 per year – more than the UK median salary £24,700. Dementia costs the UK around £20 billion a year, roughly the same as cancer and heart disease combined. 13 Most of these costs – £12.9 billion – are met by unpaid carers, with residential care making up the next biggest amount.

On a personal level, financial hardship is a stark reality for many people with dementia and their carers. The person with dementia will at some point have to give up work – so too might their carer, if adequate support cannot be found. People can find themselves facing the unexpected costs of dementia – from transport to care services to home equipment – while struggling with dramatically reduced incomes. This reflects the general financial impact of caring: three out of four carers are worse off as a result of their caring role. 14

There is currently an urgent and sometimes emotionally charged public debate about who pays for dementia care. Many charities want to see the shake-up of a system which currently differentiates between health care, which the NHS pays for, and social care, which local authorities and individuals have to fund.

Figure 2: The financial struggle for Christophe Grillet¹⁵

Christophe Grillet was diagnosed with Alzheimer's disease 17 years ago. He was receiving round-the-clock continuing healthcare from the NHS at home, but as his condition became more advanced he was reassessed and as a result the NHS-funded care with withdrawn. The NHS said that Christophe's needs were primarily social-care needs — washing, dressing, feeding and so on — and that he was relatively easy to deal with.

His wife, Kate, said: "The country is now full of people like my husband who are having their support taken away and left to try and fund whatever care they can get themselves. And I think this doesn't take into account that a person's needs are even more health needs. When you have Alzheimer's you don't get better." As a result of this home care being withdrawn, Kate had no option but to put her husband into a care home, which costs the family £600 a week, and she and her husband have been separated, which has been very distressing. "Because we didn't get the support we needed, we are separated, and that is the biggest problem," she added.

¹³ Alzheimer's Research Trust, Dementia 2010 The economic burden of dementia and associated research funding in the UK. These figures are based on an estimate that there are 821,000 patients with dementia in the UK.

¹⁴ http://www.carers.org/key-facts-about-carers

¹⁵ Ibid

3.2 What are the key issues with dementia care in the UK?

Receiving a diagnosis of dementia is often a long and difficult journey. And after diagnosis, people with dementia and carers are often baffled by the complexities of the health and social care systems. The flow chart on page 22-23 of the National Audit Office report 'Improving services and support for people with dementia' 2007 shows the maze which many people have to navigate.

http://www.nao.org.uk/publications/0607/support for people with dement.aspx

There are many challenges that the UK needs to address to improve the lives of people with dementia and their carers. Some of the most pressing ones are:

Lack of public and professional awareness and understanding of dementia

There is generally a low level of public and non-specialist professional understanding of dementia. This has many negative consequences, including reluctance among the public to go to their GP with symptoms, and uncertainty from GPs about how and whether to diagnose.

Failure to diagnose early

Between only a third and a half of all people with dementia receive a formal diagnosis at any time in their illness. ¹⁶ Reasons for this include GPs' lack of training and low confidence in diagnosing dementia. ¹⁷ There is an urgent need to address this – early diagnosis and intervention can dramatically improve quality of life for both the person with dementia and those caring for them. It can also delay admission into a care home, giving the person more time with their family. ¹⁸

Lack of information & support to navigate the system/the disease post-diagnosis

There are many reports of people being diagnosed with dementia and quickly becoming either lost in a sea of information or – worse – barely being given any. The National Dementia Strategy acknowledged the need for nationally developed but individually tailored packages of high-quality information for people diagnosed with dementia, which would build on current pockets of good practice.

Lack of support networks for people with dementia and their carers

People with dementia and their carers benefit significantly from simply being able to talk to other people in the same position. While 'dementia cafes' are

¹⁶ Alzheimer's Society, 'Dementia UK: The full report.'

¹⁷ James Sturcke, 'Britain ignoring its dementia crisis, Oxford study finds', *The Guardian*, 3 February 2010, http://www.guardian.co.uk/lifeandstyle/2010/feb/03/uk-dementia-crisis-feared-worse

¹⁸ Alzheimer's Society, 'Dementia UK: The full report.'

appearing in growing numbers around the country, such services often cater only for a very small proportion of the people who might benefit from them.¹⁹ Fostering local peer support networks for people with dementia and their carers is therefore a major priority.

Lack of respite care

Most family carers want to continue looking after their loved one with dementia at home for as long as possible. However, the current patchy provision of respite care (services that allow carers to take a break from caring) means that too often, carers simply have to weather successive crises without taking breaks. All too often this leads to early hospitalisation often, as the carer can no longer cope. Some of these crises could be prevented. So there is a need for good-quality, personalized breaks that allow carers to rest and take care of other areas of their lives outside caring.

Lack of flexible and reliable services for people living at home with dementia

The vast majority of people with dementia say living in their own homes is very important to them.²⁰ However, for many this is made impossible by lack of adequate support to help them to continue living safe and healthy lives within their communities. It's feared that 50,000 people with dementia face being forced into residential care earlier than necessary because home-care provision is sub-standard.²¹

Need for improvement in housing stock/approaches

People with dementia can benefit from the support offered in sheltered and extra care housing, but they are not always offered this opportunity. Provided appropriate opportunities for socializing are offered, sheltered housing can provided a positive environment for people with dementia. ²²

Lack of good quality care homes that can accommodate people with dementia

The fact that at least two-thirds of people with dementia live in care homes has never been planned for – which has left them profoundly unprepared. There is an urgent and widespread need for care home staff to be properly trained to look after people with dementia, and for care homes to be able to provide the range of services that people with dementia need, including psychological services from local community mental health teams.

Poor dementia-specific end-of-life care

In dementia, end-of-life planning needs to take place early, while the person has sufficient mental capacity. People with dementia and their carers need to

¹⁹ Department of Health, 'National Dementia Strategy'

²⁰ Alzheimer's Society, 'My Name is Not Dementia'

²¹ Randeep Ramesh, 'Inadequate care forcing dementia sufferers into homes early, says charity', http://www.guardian.co.uk/society/2011/jan/25/dementia-care-homes-early

²² Department of Health, 'National Dementia Strategy'

be involved early in the planning process, which should recognise the principles outlined by the Department of Health in its End of Life Care Strategy.

3.3 What kind of care services exist for people with dementia?

There are many different types of services which are available to people with dementia. These include GPs, memory services, community mental health teams, social services, intermediate care, specialist inpatient mental health wards, and – most importantly – the help of family and informal carers.

Currently many services for people with dementia are pre-purchased by local authorities. People are often 'slotted into' large scale services or offered short periods of support – often as little as 15 minutes – and in many cases with different carers visiting on a daily basis. This type of support can be detrimental to people with dementia, who are best served by routine and consistency of care in a familiar environment.

The majority of elderly people living in care homes have dementia. Among all those aged over 65 and living in EMI (elderly mentally infirm) homes, 80% have dementia. In nursing homes, two-thirds of those over 65 have dementia.

Around 208,000 people with dementia live in care homes, of whom 91,000 are in dedicated dementia care beds, but the quality of care varies. Many care homes have been rated as 'poor to inadequate' by the Commission for Social Care Inspection, particularly in the Midlands, the North East and London. ²³

3.4 What is the UK government doing to support people with dementia and their carers?

After years of what many saw as inadequate action on dementia, the UK government now has a highly ambitious and comprehensive national dementia strategy. This was published in 2009 in response to several reports criticizing the state of dementia care in the UK.

The National Dementia Strategy set out a vision for transforming dementia services with the aim of achieving better awareness of dementia, early diagnosis and high quality treatment at whatever stage of the illness and in whatever setting.

The coalition government has set out four key areas of priority for delivering the dementia strategy. These are: good-quality early diagnosis and intervention; improved quality of care in general hospitals; living well with dementia in care homes; reducing the use of antipsychotic medication.

²³ National Audit Office, Improving Dementia Services in England – an interim report, 14 Jan 2010

3.5 How well does the market for care services work?

The market for dementia care services has a number of issues that need to be dealt with. These include:

Poor quality of care

The state of social care (i.e. care delivered in people's homes) for people with dementia has been heavily criticised by the Alzheimer's Society. In a recent survey, it found that half of people living with dementia in the community are not receiving sufficient care, leading to premature hospital or residential care admissions.²⁴

Reliance on local authority commissioning

One expert interviewee for this project complained that currently local authority commissioning of dementia home care is "the only show in town", saying that there is no prospect of a vibrant market for many different innovative, everyday services for dementia while local authorities are "depressing" the market. They added that while community and voluntary providers can come up with great ideas for new services, getting funding from local authorities is currently extremely difficult.

Personal care budgets have the potential to address some of these issues. The government's vision is that people will have their own budgets which they can choose to spend on local services which best meet their needs. However, there is limited evidence on how to make this work for people with dementia, who face significant challenges in managing money and making decisions. The Alzheimer's Society has urged the government to strive to make personal budgets work for people with dementia and their carers.

Services that focus on crisis rather than early intervention

Dementia services and resources in the UK are generally not geared up to support and improve the wellbeing and quality of life of people with dementia. Instead, services and resources in dementia care have long been focused on people with complex needs and those who are facing crises in their situation – to the detriment of early intervention and prevention services. This missing support could be improving the wellbeing of people with dementia and carers. And there is also evidence that investing in services for people with lower levels of need can prevent crises and the need for costly, intensive services, such as beds in acute hospitals.²⁵

The concept of the customer

One interviewee felt that between diagnosis and the intensive needs of laterstage dementia, people with dementia and their carers were being "very poorly served" by the range of services currently on offer. Where, they asked,

²⁴ Nick Triggle, 'Dementia home support 'an absolute travesty' – charity.' *BBC News*, 25 January 2011, http://www.bbc.co.uk/news/health-12269708.

²⁵ APGD, 'The £20 billion question.'

were the services which allowed people to pursue their interests and develop new hobbies – things which could improve their health and wellbeing?

Another summed up the problem in the following way:

"We don't have a notion of the customer in social care. My advice to local authorities would be to stop commissioning an intervention and start commissioning an experience. People with dementia are currently not commissioned to have a life."

Still another said many current services bring people with dementia together simply because they have dementia – which is not necessarily helpful for them. Instead, they urged services to think about people with dementia as individuals with particular interests and aspirations – just like people without dementia:

"It's about bringing people together in meaningful ways. Just because you have dementia doesn't mean you suddenly have the same interests as everyone else with dementia!"

3.6 Assistive technology

Many products and services available to those with dementia are termed 'assistive technology'. Assistive technology is any product or service designed to enable independence for disabled and older people.²⁶ More specifically it is 'any device or system that allows an individual to perform a task that they otherwise would be unable to do, or increases the ease and safety with which the task can be performed'.²⁷

Currently there is a wide range of devices available from low-tech items such as basic mobility devices like walking sticks to more high-tech items such as automatic lighting or 'telecare'. Telecare is used to describe sensors or detectors e.g. movement, flood, gas, smoke or fall detectors that automatically send a signal via a base unit connected to a telephone line ('tele') to a carer, community alarm or monitoring service and which can call for assistance ('care') when it is needed.²⁸

Assistive technology has the potential to benefit people with dementia and their carers, for example it can enable people to live independently for longer and reduce stress on people with dementia and their carers. It can potentially enhance the quality of life for people with dementia providing them with greater choices around their care. Various reports point to the benefits of telecare, while the Department of Health is looking at the benefits of assistive technologies. Currently it is awaiting the results of the Whole System Demonstrator (WSD) programme, a two-year research project to find out how technology can help people manage their own health while maintaining their independence.

²⁶ Department of Health, Research and development work relating to assistive technology 2010-11, presented to parliament pursuant to section 22 of the Chronically Sick and Disabled Persons Act 1970

²⁷ Royal Commission on Long Term Care 1999

²⁸ AT Dementia information on assistive technology for people with dementia

However, some remain skeptical about the value of assistive technology. One expert interviewee commented:

"The whole field of assistive technology is full of quite a lot of interesting stuff ... but also full of the most appalling dull nonsense that is marketed rather than tested .. and that is a real frustration to me ...people hold out so much hope for these things but there are actually very few of them that have any real value to people, they are tremendously oversold ... it would be great if there was evidence that it does what it says its going to."

In a recent report, the Alzheimer's Society emphasised the following points with assistive technology from the perspective of people with dementia and their carers:

- Often quite a simple modification to existing technology could improve lives, without the need for expensive products, which may not be suitable in any case.
- In a University of Leeds Report on telecare for Carers Scotland, carers felt that since the introduction of telecare into their caring situation, they had benefited from more peace of mind a better night's sleep, improved the relationship with the person(s) they cared for, the opportunity to continue with activities they might otherwise have given up, the ability to remain in paid employment in some cases, and more confidence about the safety and comfort of the person they cared for.²⁹
- Carers and those with dementia express difficulties not only in obtaining an early diagnosis, but also in ensuring that assistive technology is considered as part of the intervention following diagnosis
- The lack of public awareness of assistive technology means that people with dementia and their carers do not know what to ask for.
- The priority given to assistive technology by different local authorities is variable and there is no national guidance on how assistive technology should be provided.
- Assuming that every individual with dementia requires, or will benefit from, the same piece of technology is wrong. People with dementia experience different symptoms that require different responses. Who they are, their lifestyle and their circumstances will determine the most appropriate technology. The progression of dementia will also mean that there should be a regular process of reviewing whether their assistive technology is still appropriate. Also the technology needs to be reliable, ideally with a package of training and support available to make sure the user can use and get the most from the product.

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²⁹ 'A weight off my mind': Exploring the impact and potential benefits of unpaid carers in Scotland. Carers Scotland. K Jarrold, S Yeandle 2009

- Ethical considerations feature very strongly in the debate around assisted technology, as whilst technologies should enhance and enable independence they do have the potential to produce less positive outcomes.
- The increased use of personal budgets may mean more use of assistive technologies but there are concerns that self-funders may be subject to costly products that do not match their needs.

To find out more about the types of products / services available go to:

www.livingmadeeasy.org.uk
www.allaboutequipment.org.uk
www.atdementia.org.uk
www.assist-uk.org
www.ricability.org.uk
http://www.alvolution.co.uk/compare/product_comparison_website.

4.0 Living well with dementia

4.1 What does living well with dementia mean?

Despite what most people think, dementia is not an immediate death sentence: life goes on, and can go on very well. Many people with dementia continue to be physically fit for a long time while living with dementia, and in the early stages still have significant mental abilities. With the drive towards early diagnosis, this will become even more the case.

Fundamentally people with dementia are unique adults whose wishes, wants and needs remain worthy of respect – and are capable of being fulfilled. For a long time, people with dementia – particularly Alzheimer's disease – can be perfectly healthy, despite the erosion of their mental abilities. While someone might not be able to recognise their spouse most of the time, they may still be able to walk, sing, dance, paint – or enjoy many other activities. While dementia will have an impact on a person's abilities as it develops, there will still be lots that the person can enjoy doing, both individually and with others. Maintaining existing skills, as far as possible, can bring pleasure and boost confidence. ³⁰

The point to remember is this: people with dementia are not *defined* by dementia. It's essential that there are services available that help people with dementia to enjoy the maximum quality of life possible – rather than just those which provide for immediate medical and social needs.³¹

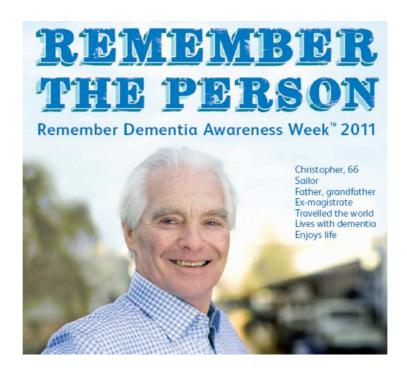
Speaking with experts for this project, we found some agreement about what 'living well with dementia' means. One said it's about "being accepted into the community", and being able to access the services you have always used – banks, supermarkets, high street shops, public transport and so on. Another said it means nothing less than what living well means for everyone else. "It's about maximizing the potential of your human life. Still doing what you want to do. It's about society still viewing you as a unique person. It's about how people help you make sense of the world on a day-to-day basis."

Another stressed the importance of "still having a function within the family and within the community." Indeed, work by Professor Gail Mountain at the University of Sheffield mentions the strong interest that some people with dementia have to get involved in volunteering type activities.

People with dementia and their carers also talk about the importance of maintaining aspirations – of trying new things, or continuing with existing hobbies and interests.

³⁰ Alzheimer's Society, 'Keeping active and staying involved', http://www.alzheimers.org.uk/site/scripts/documents info.php?documentID=90 (last accessed 27 July 2011).

³¹ Ibid.



As part of its Remember the Person campaign, the Alzheimer's Society interviewed the family and friends of a woman with dementia, who made this point very clearly:

"Sue hasn't lost any of the personality that was always there. She's still funny and she still wants to go out and do things, and that's the way I think it's important to treat anybody who is diagnosed with dementia. They're the same person. They're struggling with a condition that's hard sometimes to cope with, but the person behind that is still there." (Friend)

"She still wants to live her life and be out there and be happy." (Daughter)

"Look at the person and the life they've always lived and what they want to continue doing." (Friend)

The organisation Innovations in Dementia have produced a series of short films made with people by dementia, which give them the opportunity to show that, despite their diagnosis, they are living rich and meaningful lives. "Listen to me, just listen to me," says Peter, who had an illustrious career as a sculptor and educator, as his film begins, "and you'll understand what I'm saying." The film follows Peter around his studio while he talks lucidly about the events that shaped his life and career.

Another film follows a group of people with dementia on a walk across the Wiltshire countryside. At one point one person with dementia asks the group leader: "Why is it that we're doing this and other people are sitting around in a room with the TV set on [even though] there's the same amount of staff?" She replies that it is because people "like to make judgments about ill people" and that in trying to do everything for people with dementia, they stop them from feeling like they can still do things themselves and live reasonably independent lives. The film also features people with dementia and carers talking about the benefits of staying positive.

The films are available to watch here: http://www.innovationsindementia.org.uk/videos.htm

For people in the early stages of dementia, things like going on holiday are also still possible – they may want to travel and see new places while the opportunity is still available. Although, much of the advice here stresses that since dementia can cause confusion, disorientation and anxiety, traveling alone is something do be done with caution. The Alzheimer's Society suggests that when partners are taking their spouses with dementia on holiday, they may want to consider bringing along another friend or relative to provide extra support.³²

There are not large numbers of specialist holiday and travel services for people with dementia. However, companies such as Vitalise provide specialist holidays for people with disabilities and their carers, with centres across the UK.³³ For example, it offers breaks at five purpose-built centres in the UK for people with dementia and their carers.

4.2 What are the barriers that currently make it harder for people with dementia to live well?

Despite all the issues associated with accessing care and support services, the main issues which people with dementia commonly face are **stigma**, **isolation**, **loneliness and social exclusion**. After diagnosis, people often experience changes in the way some of their family members and friends treat them. They may find themselves not invited to social occasions – or turning down invitations for fear of causing embarrassment. Terry Pratchett sums up the social stigma in this way: "With cancer, hope exists – and when you've got cancer you're a brave battler. When you've got Alzheimer's you're an old fart."³⁴

These attitudes are profoundly upsetting for people with dementia and their partners. Many come to feel very alone and excluded from their previous lifestyle.³⁵ In a recent survey by the Alzheimer's Society, carer respondents felt people with dementia generally were being excluded from the community.³⁶

When asked what people with dementia wanted most, one interviewee put it very simply: "They want people. They want human contact. If you could come up with an innovation for kindness, that would help. If you could come up with an innovation that would make people be a little nicer to people with dementia, that would help." The interviewee has spent many years working with people with dementia and their carers.

³² Alzheimer's Society, 'Traveling and going on holiday', http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=158 (last accessed 27 July 2011).

³³ http://www.vitalise.org.uk/

³⁴ Terry Pratchett – 'Out of the Shadows – diagnosis', http://www.youtube.com/watch?v=sUHARRJhjso&feature=relmfu (last accessed 27 July 2011).

³⁵ NAO, 'Final Report – Dementia Focus Groups Findings'

³⁶ Alzheimer's Society, 'Support. Stay. Save.'

Another interviewee who works in older adult psychology said that in their experience, the most commonly reported issues from people with dementia are loneliness and isolation, and the depression which they cause. Addressing this would be a major step towards improving quality of life for many people with dementia.

'One of the things we experience is people's disbelief that you have dementia because you're appearing normal. It's so frustrating.' (Person with early stage dementia)³⁷

'It's as though that's it, you are dribbling and nodding, and that's Alzheimer's. That's the picture of Alzheimer's. But we are sitting all here talking perfectly normally. We have got Alzheimer's of some form, we are not nodding and dribbling.' (Person with dementia)³⁸

4.3 What are the particular issues for people with dementia from BME communities?

While the issues outlined above apply to almost everyone with dementia, there are some problems which specifically affect black and minority (BME) communities. These include a lack of culturally, linguistically and religiously appropriate services. Other problems, which need to be worked with, include a lack of knowledge about dementia and – in many cases – a particularly acute stigma attached to it.

Interviewees said that families in BME communities are likely to want to keep their relative with dementia inside the house and away from both their community and from healthcare professionals. This was largely because of the shame and stigma attached to dementia, and to a reluctance to accept it as a natural, medical condition, rather than a personal failing. Social isolation is therefore a key issue for people from BME communities who are living with dementia.

4.4 What support services are available to people with dementia?

People with dementia and their carers benefit significantly from simply being able to talk to other people in the same position, whether that's to exchange practical advice or provide emotional support. The main kinds of support services currently available include:

Internet forums

Internet forums allow people with dementia and their carers to share experiences and advice, and provide each other with emotional support. The Alzheimer's Society's Talking Point forum was launched in 2004 and now has over 14,000 active members. The key benefit of such forums is that they are

³⁷ Ibid.

³⁸ Alzheimer's Society, 'Out of the Shadows'

accessible 24/7 so people can seek help and advice whenever it is needed. Online forums are also particularly helpful for people who do not want to call telephone help lines.

Dementia cafes

There is a network of dementia cafes around the UK, which provide a safe and informal environment where people with dementia and their carers can receive advice and support. There are around 20 based on the Alzheimer Café model, which run an annual programme of talks and discussions covering the journey through dementia. Invited speakers lead discussions in an accessible and supportive atmosphere. There is also a more informal network of cafes, which focus on more informal support and information giving. These have names such as the Memory Lane Café, Forget Me Not Café, and the Friday Coffee Club.

Befriending services

Befriending services provide one-to-one support for socially isolated people with dementia. The aim is to provide both company and activity, by supporting people in their activities and interests, providing access to their local community, and signposting to relevant services when issues and concerns arise.

5.0 Caring for someone with dementia

5.1 Being a carer

Caring for someone with dementia involves an extraordinary range of experiences, emotions and challenges. The person will be providing an increasing amount of support for their partner, relative or friend – while at the same time dealing with their own emotional issues. They have to cope with changes in their relationship with the person with dementia, and the loss of cherished future plans.³⁹ Caring has an impact across many areas of a carer's life, including their emotional and physical wellbeing, and their professional and financial status. Despite these difficulties, caring also has positive sides. Many carers say their caring role gives them great satisfaction: it makes them feel needed and useful, and lets them express their love for the person. It can bring them closer to their loved one in a new way.

Most family carers want to be able to provide support to help the person with dementia stay at home, but very often this is difficult. More than half of carers say they are not getting enough support to carry out their caring role: this is frequently believed to result in admission to hospital or care for the person with dementia – both of which could perhaps have been avoided. If carers are not supported properly their physical and mental health can suffer – in turn, this can impact on the person with dementia.

Financial hardship is unavoidable for many carers. People often find themselves in situations where they have to leave their job to look after a spouse or parent, sacrificing their pension, job security and career progression in the process. The majority of carers in the UK are women. Since women tend to live longer than men, female carers who have already stopped contributing personal pensions to take up caring are placed in a particularly vulnerable position.⁴⁰

The Alzheimer's Society has produced this factsheet for carers which sets out ways for looking after yourself: http://www.alzheimers.org.uk/site/scripts/ documents info.php?documentID=119

What support services are available to the carers of those with dementia?

Many of the services, which are available to people with dementia, help support their carers too. For example, online forums are used by carers and people with dementia alike. (You can watch an interview here with a carer

³⁹ See, for example, Schneider J, Murray J, Banerjee S and Mann A (1999) EUROCARE: a cross-national study of co-resident spouse carers for people with Alzheimer's disease: I – Factors associated with carer burden International Journal of Geriatric Psychiatry

^{14(8): 651-61. -} originally cited in Nuffield Council, 'Dementia: Ethical Issues.'

⁴⁰ Alzheimer's Society, 'Carer Support position statement', http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=546

discussing how important the Alzheimer's Society's Talking Point forum was to her when caring for her husband: http://www.youtube.com/watch? v=3pub4yP-Nxw). Likewise, dementia cafes are places where carers can meet other carers and get support and advice from healthcare professionals.

Other services, which are available to carers, can include:

Respite care and breaks

Respite care is short-term care used as a temporary alternative to a person's usual care arrangements. People who care for someone with dementia often carry on without realising how tired or tense they have become. It's essential that they are given opportunities to relax, recuperate and take care of other commitments. Respite care is also needed in other situations, such as when the carer themselves needs to go into hospital. There is a widely acknowledged lack of good quality respite care services in many areas.

For more information on respite care, read this Alzheimer's Society factsheet: http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=140

Admiral nurses

Admiral Nurses are specialist dementia nurses who support the relatives of people with dementia. They build close personal relationships with family carers and help them to support their loved one in living positively with dementia. They provide advice and teach them vital caring skills, however there are relatively few of these nurses across the UK.

Information and training

There is a range of information available for carers of people with dementia. However, some research has suggested that only a third of carers were told how to care for their relative or how to cope with dementia by health professionals they dealt with.⁴¹ The National Dementia Strategy has since identified this need as a major priority.

Assessment of needs and support packages

Although carers are entitled to an assessment of their needs and a tailored package of support, the Alzheimer's Society found recently that only 37% of carers report that they have had an assessment and receive social services support.

Charities

There is an abundance of testimonies from people with dementia and their carers, which demonstrate the vital role, that charities – particularly the Alzheimer's Society, but also Carers UK, Dementia UK, and many other smaller groups – play in supporting them through their experience with dementia.

⁴¹ NAO (2000) cited by Alzheimer's Society, 'Carer Support position statement'

5.3 What are the core principles of caring for someone with dementia and their carer?

Clinicians and other health professionals agree on certain core principles which underpin the best possible care for people with dementia, and the best support for their carers. They are:

- The human value of people with dementia, regardless of age or cognitive impairment, and those who care for them;
- The individuality of people with dementia, with their unique personality and life experiences among the influences on their response to the dementia;
- The importance of the perspective of the person with dementia;
- The importance of relationships and interactions with others to the person with dementia, and their potential for promoting well-being.⁴²

For more information on understanding and respecting the person with dementia, read this factsheet by the Alzheimer's Society: http://www.alzheimers.org.uk/site/scripts/documents info.php?documentID=84

How can people with dementia and their carers be supported to make decisions around care?

Recent government guidance recommends that people with dementia are encouraged to express their views and be included in decisions about their care. One useful innovation in this area is Talking Mats, a low-technology communication tool which helps people with communication difficulties express their views. Talking Mats use a simple system of picture symbols, placed on a textured mat, which allow people to indicate their views about various options within a topic by placing the relevant image below a visual scale.

⁴² NICE (2006). 'NICE clinical guideline 42. Dementia: Supporting people with dementia and their carers in health and social care.'

Insert 2: Carer stories: Manjit Nijar, Michelle Poole & Jim Swift

(From Dementia UK - http://www.dementiauk.org/what-we-do/uniting-carers/carers-experiences/)

Manjit Nijjar's Story

My parents came to England in the 1960s. My Dad came here having served in the British Indian Army. He was the most fearless man I ever knew. Dad and I had an incredibly close relationship; in fact I'd say he was my best friend growing up. When I was 15 or 16 years old the spectre of marriage was on the horizon and my friends were all getting engaged. Instead of encouraging me to follow suit Dad pulled me to one side and said: "Manji, I think it's about time you ran away from home!"

In late 2004 it became glaringly obvious something was wrong. Mum and I had gradually adjusted our lives to accommodate Dad's changing needs without even realising it. Dad had gone to bed and suddenly started shouting and banging saying he wanted to get out but he couldn't find the door. Dad had become afraid of the dark. He never slept in his bedroom again. 2005 followed in the same vein. In February Mum was diagnosed with terminal cancer and given less than 6 months to live. In May Dad was given a preliminary diagnosis of Alzheimer's and vascular dementia. In June Mum died.

None of my Dad's friends would accept that he was ill. They would cross the street to avoid him causing more distress and anxiety, as he did not understand their behaviour. As far as they were concerned he was cursed and had bad karma. The fact that he had been an active member of the community for over 40 years became irrelevant and all the support he needed after Mum's death evaporated. On one hand I couldn't really blame Dad's friends as they didn't understand what dementia was. You see there is no word for dementia in the Asian languages. So the word mostly commonly used to describe dementia is the same word for insanity. As far as they were concerned Dad had become infected with madness and it is not only contagious but also could be hereditary. It did not, however, stop people from giving me remedies to cure him including rubbing his head with almond oil, putting almond oil in his tea, and putting turmeric in warm milk for him to drink. I have to admit that I had special prayers said for him both in India and in a local Gurdwara, partly in hope of a cure and partly because of our faith. He was Dad and I needed him especially as Mum had just died.

Dad had always been a religious man so I would take him to our local Gurdwara. He needed assistance with eating so I would feed him Prasad, which is the Sikh equivalent of the Holy Communion. On one particular occasion the congregation had left but I was still feeding Dad. The priest came and turned off the lights. So there we were, Dad and I sitting in the dark all alone. This summed up for me what it was to be Asian, have dementia and to be a carer. In a flick of a switch we were became invisible and worthless. It was an incredibly lonely and isolating time for us.

Trying to access day care services for my Dad brought it's own problems. After all don't "Asians take care of their own?". There is a perception amongst statutory bodies that Asian communities don't use services because of extended family networks. Well my brother lives in Canada and we have no family living in the U.K. Even if I had family here there is nothing to say that they would have cared for Dad.

In that sense are we any different than any other community living in the U.K.? The reality was that I felt condemned by the perceptions of the Asian community and those of the statutory bodies which meant that I had no one to turn to, no support at a time of great need. To have had someone to listen to me and help me would have allowed me to focus on Dad and support him better.

Day care became very important to me because I was working full time and I was worried about Dad's safety as he wandered around the streets of Wolverhampton. It wasn't until Dad had been beaten up and been hit by a car before I got the full day care provision for him. I could finally breathe knowing that he was safe. I knew Dad better than anyone else and what he needed was to be at home. All Dad and I needed was more support at an earlier stage to avoid the inevitable crisis upon crisis that rained down on us.

To compound the issue when dad was finally allocated a day care I was asked "Why have you 'thrown your father away"? by members of the Asian community who knew him. Even though Dad has now gone I am constantly being told that I have failed him.

Caring for Dad has changed my personal and professional life. I decided to make a difference by working in a third sector organisation, with the Asian community in Wolverhampton. In my job I am trying to provide the support that Dad and I lacked so desperately. This involves raising awareness of dementia, helping carers by providing support and advice in a culturally appropriate manner. There are no flashy gimmicks or lavish productions here.

- It's about opening the hearts and minds of Asian people through information.
- Breaking down the prejudice and tackling the fear associated with dementia
- Showing pictures of a healthy brain compared to one with dementia.
- Emphasising that dementia is a physical illness not a mental heath problem or madness.
- Where appropriate talking to the whole family and not just to a couple of members
- Providing Caring and Coping with Loss in Dementia for Asian Carers by Asian carers.
- Trying to reduce the stigma of day care by encouraging older carers to attend day care services with their spouse so it's a day out instead of an issue of abandonment.
- Working with Statutory bodies to improve services.

In this time of austerity when services are being cut and carers find they are fighting for everything, hard to reach communities become harder to reach. The fear of dementia and all that it can mean for a community can lead to greater isolation. The people with dementia and their carers within those communities become more marginalized and less visible.

Michelle Poole's Story

My dementia journey began years ago. It was a sharp learning curve. I had to;

- 1. Understand dementia and how it affected my mum
- 2. Understand and accept what it means to be a carer
- 3. Realise that so many health care professionals on whom I rely, often don't understand and lack training......The insistence on providing just sandwiches for every meal eventually caused my mum to rebel and stop eating, she dramatically lost weight..2st in 2 months.

My mother has mixed type vascular dementia with Alzheimer's and was diagnosed in 2004. She's 88, lives alone and I'm her principle carer. I often feel I'm the only thing standing between her and residential care, my mother does not want to go into a residential home and she's told me often. She has told me she wants to die in her own home.

I've had the advantage of courses and Joe's Club, a support group run by the Admiral Nurses for carers of people with dementia. Sharing many different stories, and different strategies with other carers..... a safe place to let off steam. I've learnt a lot. Getting to understand my reactions, feelings and learning how to cope has been important part of learning about dementia. The more I learnt, the more I became involved. Gaining support, that knowledge and getting involved with Uniting Carers has given me the confidence to speak out.

For years I struggled on my own, trying to keep all the balls in the air, even moving to be closer. It took a while for my sisters to understand, they would argue and challenge what was going on. I felt it was so important to pass on my knowledge; I wanted to get it right and so often it came out wrong. It was a huge relief when one of my sisters joined me recently as a carer.

Becoming my mother's carer, something I never expected nor sought, struck right to the heart of our relationship. Never an easy one. An ironic role reversal meant I became the reluctant mother and she the rebellious child. But I'm still her daughter. Many times I would walk away fuming or desperately upset not just by her behaviour, but also by the legacy of past injustices. I felt so guilty about my anger and frustration. Questioning myself. Am I the only one feeling like this? Other carers seemed so saintly.

Strange that now I'm the one she really needs and appreciates. It seemed everything I did she would undo. Wiping clean the info board. Opening the locked medicine box with a knife and taking all the medication at once. Removing the new microwave by hauling it to the top of the stairs to the top of the stairs. The lockable fridge to keep food in one place, she cracked that too. Losing keys, locking herself in or out. Locksmiths did well out of us! I know about Black holes in space, there's one in my mum's flat and everything ends up in it at some point! Over time and with support I've developed many practical and emotional strategies to keep one step ahead and to keep caring. Like hiding a 2nd fridge in a cupboard. Installing a Key safe, key pads and a safe for medication. It is a constant challenge because strategies, like the keys, don't stay in place.

In learning not to overreact and get so upset, and being calm. I am finding new ways of communicating with my mother. Last week, for the 1st time, I invited my mum to help me prepare her some scrambled eggs on toast. I was delighted and so was she when she beat the eggs and then cooked them to perfection. The time, responsibility and sheer quantity of events can be overwhelming.

Mum's psychiatrist said she has moderate dementia, is in good health and could go on for 10 years more. Imagine! I'll be 75 and mum will be 99! It's hard enough caring for someone with dementia without having to battle and worry about care services going wrong, especially as I rely on other care professionals.

I'm constantly reminded of how dementia is so badly understood. The other day a new care worker took my mums assertion that she cooks her own food, at face value, and didn't offer her anything to eat. Mum didn't eat for 2 days. Good job I called in! Lack of training and understanding gets in the way of good care.

My Admiral Nurse has helped me ensure my mother's needs and wishes are met. Supporting me as I plot my way through all the services involved in my mother's care one way or the other. Her advocacy role in the review meetings, formal complaints procedure, Vulnerable Adults Service, psychiatrists, social workers, police and many other agencies has been invaluable.

In Conclusion, I've been lucky to have that support and advocacy. So many carers don't have anything. Even with support, it is still difficult. Family carers must not be left on their own to struggle and burn out. Carers know a lot and do a lot. Family carers already save millions. It is time we all got a better deal and some real support. The knowledge and support I've gained keeps me sane and mum at home. We need skilled and trained professionals to work in partnership with us if we are to continue as family carers. Diminishing resources and increasing demands are sobering. The challenge is to fund and develop those meaningful partnerships. Indeed, it is vital to us all.

Jim Swift's Story

Some dates are forever seared into your memory. For me just such a date is Thursday 11th April 2002. This was the day I learned that my wife, Jan, had dementia. She was 58 years old.

In my career I was a head teacher and as such I was used to meeting problems, be it with parents, pupils or staff and dealing with them. Now I was meeting the greatest problem of my life and I was impotent. More than that..... I felt alone.

However the disease manifests itself, Alzheimer's can expose carers to a ruthless, unrelenting and deepening nightmare. It is they who have to bear the brunt of looking after their loved ones and to endure the emotional and physical torment each day, as every vestige of humanity is slowly stripped away. Therefore to try to ensure that we carers are afforded the help we need, we have to tell our individual stories to demonstrate exactly what day-to-day life is like caring for someone with dementia.

Often articles about dementia are sanitised versions of the real experience. They do not often mention dealing with excrement and urine and neither, for the relationship between husband and wife, do they mention the cessation of sexual intimacy. The violent outbursts that you have to deal with, where your wife, with face contorted with rage, lashes out physically and tells you that she hates you, that you are horrible, can also be glossed over. If we want to portray this disease as it really is, in all its darkest forms, we must be prepared to tell the whole story.

Let me tell you about some of the events I experienced with Jan last week. Jan is now incontinent and at two in the morning I took her to the toilet. Her nightie was a little wet so I took it off. She refused my efforts to put another one on her. Going back to bed she refused to lie down and after a while got out of bed again and paced the room. This pattern of bed / pacing continued for two hours. That evening Jan could not settle to watch T.V. or listen to music and the pacing began again. In the toilet, at bedtime, Jan would not lift up her feet in order that I might remove her knickers. This non compliance after long entreaties rendered me so frustrated that I shouted at her in anger. Jan then sank to the floor and refused all my attempts to get her up and attacked me when I tried to help her. The guilt that you feel when you lose control like this is one of the worst aspects of the disease.

In her career Jan taught hundreds of children to read, write and compute. Now her own abilities are far less than theirs. This once caring, confident, articulate and intelligent woman is now unable to read, write or hold a conversation. She cannot find her own clothes, dress or undress herself, make a cup of tea or even dry the dishes. In the evening I am alone as Jan becomes more silent and introverted.

Luckily I was introduced to Dementia UK and the Admiral Nurse Service. I have to say now, that I would not have been able to get this far with Jan's illness without the help, advice and support of the Admiral Nurse Service in Bolton and in particular Paula Smith, my Admiral Nurse. Her advice, expertise, professionalism, care and compassion have guided me and given me the strength to get this far. Her understanding and knowledge have taken me sometimes where I didn't want to go but she knew better than I how, when and where help was needed. She continues to be the rock to which I cling when the going gets tough.

So what would ease the burden and give both Jan and I a better quality of life? I have first of all to say that I already have access to many of the services I am going to request but the point is that this is solely because of where I live. I am lucky, but the majority of carers are not and even so, coping day after day, is still a struggle. What would have a far greater impact with regard to best care for carers and dementia suffers alike is for the government to remember their A B C.

A, as I hope I have demonstrated, would be an increase in the Admiral Nurse Service. Why not develop and expand an organisation that is already up and working and of proven worth?

B, would mean an increase in benefits. I don't want an increase to buy my wife expensive presents but I do need to make her last years as comfortable as possible without financial worries. I can not bear the thought of Jan having to enter a home. It would feel as though I had betrayed and abandoned her and so I have spent all our savings on the construction of a downstairs bedroom and walk-in shower, so now monetary considerations are of paramount importance.

And finally C, would be the C of the Carer's Allowance which will disappear when I reach the age of sixty-five, as I will then be in receipt of my state pension. It is an allowance for caring. I am obviously going to continue to care for my wife after I reach sixty-five and surely my state pension was to allow me some quality of life in old age.

C would also stand for increased and easier access to care support. A carer told me recently there are those people who can cope alone and those who can't. He was wrong. Even an Olympic athlete would buckle under the emotional and physical strain.

This is not a forum that I ever imagined speaking at. It is not the retirement, that I had sketched out for Jan and I. It is hard to remember what my original Jan was like, except when we watch home videos but I can't bear to watch for long as the difference between Jan then and now is too stark and painful. Jan has never known that she has the disease so we have not been able to cry together. I treasure every moment but even after seven years I wake up devastated by this illness that has blighted our lives.

About the only ability still remaining to Jan is her recognition of the love she has for me and the memory of my face. I know that the latter will eventually disappear but I have to believe that her love for me will never die. The Jan that I married over forty years ago was the love of my life. The Jan that I have now, although vastly different, is still the love of my life.

6.0 Some examples to think about

6.1 Dementia care

Good practice examples of dementia care exist across the UK, please see the Department of Health Good Practice Compendium for detailed examples:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/ PublicationsPolicyAndGuidance/DH_123476

For more examples of regional activity go to the Yorkshire & Humber Improvement Partnership, Inspiring Innovation in Dementia Regional Directory for 2010:

http://www.yhip.org.uk/silo/files/yhip-dementia-innovation-directory.pdf

The examples in these documents and others are working hard to improve and develop dementia care. Interesting examples of this type of activity include:

- In Waveney Surrey, the local authority has developed a service commissioned from an independent domiciliary care agency to support people through moment of crisis rather than allowing the crises to develop and result in admissions to hospital or residential care
- Age Concern in Lancashire, have developed a service which enables individuals who are experiencing the early stages of dementia type illness to have support in continuing to pursue interests, maintain their independence, and retain / or develop social contacts
- A Community Memory Therapy Service in Doncaster has worked with a local school to develop an intergenerational project, setting out to reduce stigma around dementia and raise the self-esteem of those with dementia
- Alzheimer's Society in North Yorkshire, have developed a befriending service to help people with dementia sustain their involvement in the local community as well as continue to access hobbies
- Calderdale NHS have developed a dance and movement psychotherapy service as part of their day-centre services for those with dementia

6.2 Social care

There are a number of innovations within social care that are being trialled for appropriateness to dementia care through the work of Innovations in Dementia:

Shared Lives

Shared lives is a type of living arrangement that organises permanent or short stays in the home of a local family. The person is welcomed as a member of the family. The family is checked and approved, trained and monitored by a Shared Lives Scheme.

Innovations in Dementia is working with SWAPS (South West Adult Placement) on developing a Shared Lives Scheme for people with dementia. Shared lives has traditionally been a service for people with learning disabilities. Innovations in Dementia SWAPs have got three years funding from the Esmee Fairburn Foundation to look at developing 'Shared Lives' opportunities for people with dementia.

To find out more: http://www.innovationsindementia.org.uk/
projects communities.htm

Circles of Support

When people develop dementia they often find their personal networks of support get smaller. Families and friends may be reluctant to help, frightened by the condition or unable to see how they could contribute. As a result many people with dementia miss out on opportunities for support and advice and can become isolated, depressed and vulnerable to other health issues. People with dementia and their families tend to manage alone. Circles of support is an established model in social care more generally of enabling older and disabled people to lead the lives they want to lead. Innovations in Dementia is now running a project to see how this concept will work with people with dementia.

To find out more: http://www.ndti.org.uk/major-projects/circles-of-support-for-people-with-dementia/

Other interesting approaches in social care include:

Homeshare

Homeshare provides housing in exchange for help in the home. A householder offers free or low-cost accommodation in exchange for an agreed level of support. Homeshare provides a solution to the needs of two groups of people - those in need of affordable housing, and those in need of support to live at home. Homeshare programmes have taken root in thirteen countries worldwide.

To find out more: www.homeshare.org.uk

6.3 Other interesting examples

When thinking through thorny problems, it often helps to reflect on examples of innovation, so please find below some interesting examples to get you thinking:

Elder power

Elder Power is dedicated to enabling elders to remain in their homes for as long as possible, and to keep them connected to their families, friends, interests and communities. They offer a variety of interdependent solutions which incorporate family connections and community activities with the use of on-site caregivers and appropriate technologies.

Elder Power is a unique social network designed to support older people who want to remain in their own homes as they age. The network is composed of members, family, friends, neighbours, volunteers, and professionals and it is through this network that a range of support services (transportation, errands, meal preparation, laundry, housekeeping, repairs) are provided. Services are intended to help members take control of their lives and members are expected to be responsible for, and take an active role in, their own well-being and are encouraged to help others as well as help themselves. Professional support is provided when necessary, but Elder Power is neither a medical program nor a provider of home health care. It offers a wide range of technologies to make it easier for members to feel safe and secure and teaches members and their families how to us these tools.

All Elder Power members are eligible to receive:

- A Personal Member Advocate
- 2X/ day phone calls
- Guardian 911 Emergency Response System
- Remote video monitoring
- Home visits
- Weekly transportation or errand service
- Personal Weekly Planner
- Monthly Community Activity Calendar
- Video Calling
- Semi-Annual Mental Health Assessments
- Access to Website and Email
- Access to Elder Power TV
- Use of Elder Power Social Network

Why it interests us:

Elder Power provides an innovative way to combine the most important elements of life; enabling people to be safe and comfortable in their own home at the same time as maintaining meaningful social connections and ensuring personal needs are met.

Find out more: http://www.lincme.net/

Beacon Hill

Beacon Hill Village is a membership organisation in the heart of Boston, USA. It was founded in 2001 by a group of long-time Beacon Hill residents as an alternative to moving from their houses to retirement or assisted living communities. By organizing and delivering programs and services, Beacon Hill Village allows a growing and diverse group of Boston residents to lead safe, healthy, and productive lives in their own homes as they age. Members are 50 years or older, single and married. From groceries to Tai Chi, to cultural and social activities, to home care, Beacon Hill Village members get support through this network to help them to live well.

Members can access:

Wellness Options: Exercise classes, Discounts at local health and fitness clubs, Personal trainers, discounted, Access to Senior Health practice at Massachusetts General Hospital

Home healthcare providers, discounted: Wellness seminars by experts, MGH Executive Registry: access to health care internationally

Geriatric Care Management for Members and their Loved Ones

Transportation: Rides for grocery shopping, Member-discounted limo and taxi services, Hospital/Doctor-prescribed rides, Rides to anywhere, anytime

Household Tasks and Services: Home repairs and adaptation, Household tasks: cleaning, cooking, organizing, Routine cleaning and heavy clean outs, Computer assistance, Home office: bill-paying and financial organizing

Meals and Groceries: Weekly transportation to grocery stores, Referrals for catering services: delivery or home preparation

Member-discounts at local restaurants, luncheon club

Social, Cultural, and Special Events: Private tours to museums and art shows, "Conversations with...." Intimate evenings with Boston notables, Trips for BHV members to concerts, and cultural events in the region, Educational seminars, Travel club, singles, film, lunch, and dinner group, Special interest groups, e.g., travel, bridge, politics, theater and film

Friends: New friends and new ideas, perhaps the most valuable benefits of all

Why it interests us:

Beacon Hill Village demonstrates how communities can come together to support one another to access services and support one another to stay involved in their community and live well.

Find out more: http://www.beaconhillvillage.org/

ITN America

Independent Transportation Network® (ITN) provides transport with 'door-to-door', 'arm-through-arm' service to thousands of older people across America. It offers programs that allow older people to trade their own cars to pay for transportation needs, and enables volunteer drivers to store transportation credits for their own future transportation needs. ITN's Road Scholarship Program converts volunteer credits into a fund for low-income riders, and the gift certificate program helps adult children support their parents' transportation needs from across the street or across the nation.

Why it interests us:

ITN America is interesting due to the model that it operates; it's a volunteer-based, credit-transaction transport service for older people.

Find out more: http://www.itnamerica.org/

GlowCaps

GlowCaps fit popular prescription bottles available in the US at Walgreens and other retail pharmacies. Inside the GlowCap is a wireless chip that enables four services. Collectively, the services help people to take their medication on time. The intelligent pill caps, which use flashing lights and audio reminders, as well as phone calls and SMS, to remind forgetful patients that it's time to take their medication, sell at between \$10 and \$15 a month through a Vitality connectivity service plan. Basically, your pill bottle lights up and chimes when it's time for your medication. As soon as you open the bottle, adherence data is then sent via AT&T to Vitality, who then pass that data on to you, your doctor, and any other approved party, in the form of progress reports. They're also equipped to automatically refill your prescription when the bottle gets low.

Why it interests us:

GlowCaps are an interesting example of a product with wrap-around services that encourage certain behaviours which ensure that medication is taken when it should be.

Find out more: http://www.rxvitality.com/

Adeg Supermarkets (Austria)

To please and accommodate older people, Adeg incorporated a wide variety of features: reduced-glare lighting, slip-proof flooring, wider aisles, easier-to-navigate parking spaces, reduced-height shelving, pleasant places to sit and signage and shelf markers in larger type. Stores also offer several cart and basket options, including a shopping cart that attaches to a wheelchair and another that has a fold-down seat for shoppers who might want to rest along the way. The produce display is engineered so that even a person in a

motorized vehicle or wheelchair can select his or her own items. Shoppers can borrow reading glasses to check small print on labels or use magnifying glasses that are attached to shelves in some areas. Smaller packages of things like cheese are intended to serve households of one or two. All employees are over 50.

Why it interests us:

Adeg Supermarkets are of interest as their whole shopping experience has been tailored to be a great experience for older consumers – what can UK retailers learn from Adeg?

Find out more: http://www.springwise.com/retail/supermarkets_for_seniors/

Ruby Slippers

Ruby Slippers specialises in combining good design with practical functionality that can help people enjoy their home throughout their retirement years. At the heart of the Ruby Slippers service is a concept it calls "ageless design," which essentially boils down to accommodating the effects of aging in an invisible way through smart design features that are not just stylish but also geared toward safety and comfort. They provide help with areas of the home such as kitchens, bathrooms etc

Why it interests us:

Older consumers are increasingly savvy. Ruby Slippers demonstrates that it is possible to offer them solutions that are not only functional but also well designed.

Find out more: http://www.rubyss.co.uk/

ConnectAde

Many adults tend to think that finding suitable housing is the main challenge in caring for aging parents, however there are also a variety of medical, legal and financial decisions to be made. That's where Michigan-based ConnectAde comes in, with a step-by-step process that's designed to make the process easier. Users begin by entering their ZIP code along with their loved one's primary ailment and an email address. The free site then creates a Care Action Plan specific to the user's needs and geographic location, complete with next steps to take and local providers who can offer assistance. ConnectAde also seeks to consolidate the communications around care giving, helping to keep everyone who needs to be, informed about their loved one.

Why it interests us:

ConnectAde is an interesting web based example that can support carers to find information on available services, as well as helping them keep the wider family network abreast of what's going on.

Find out more: http://connectade.com/

Men's Sheds Australia

The modern Men's Shed is an updated version of the shed in the backyard that has long been a part of Australian culture. So what is so special about this new type of Men's Shed? Most men have learned from our culture that they don't talk about feelings and emotions. There has been little encouragement for men to take an interest in their own health and well-being. Unlike women, most men are reluctant to talk about their emotions and that means that they usually don't ask for help. Probably because of this many men are less healthy than women, they drink more, take more risks and they suffer more from isolation, loneliness and depression.

Because men don't make a fuss about their problems, these problems have consistently been either ignored or swept under the mat by both our health system and our modern society. It's time for a change and the Men's Shed movement is one of the most powerful tools we have in helping men to once again become valued and valuable members of our community.

Good health is based on many factors including feeling good about yourself, being productive and valuable to your community, connecting to friends and maintaining an active body and an active mind. Becoming a member of a Men's Shed gives a man that safe and busy environment where he can find many of these things in an atmosphere of old-fashioned mateship. And, importantly, there is no pressure. Men can just come and have a yarn and a cuppa if that is all they're looking for.

Following the highly successful Men's Sheds scheme in Australia, Age Concern in the UK has developed the idea. In Exeter the 'Men in Sheds' scheme renovates hand tools for dispatch to poor communities in Africa.

Why it interests us:

Men's Sheds is inspiring as it is a simple yet effective concept that is having a very positive impact.

<u>Find out more: http://www.ageuk.org.uk/professional-resources-home/conferences/discovering-mens-sheds/</u>

Fureai Kippu, Japan

Translated as "elderly care units" or, more charmingly, "kindness tickets", Fureai Kippu is a nationwide Japanese system of local alternative currencies to help care for elderly people. One currency unit represents an hour of service to an elderly person. Sometimes older people help each other and earn the credits, other times family members in other communities earn credits and transfer them to their parents who live elsewhere. For example, an elderly woman who no longer has a driver's license; if you shop for her, you get credit for that, based on the kind of service and the number of hours. These credits accumulate- users may keep them for when they become sick or elderly themselves, then use the credits in exchange for services. Alternatively, the users may transfer credits to someone else.

A surprising part of the project has been that the elderly tend to prefer the services provided by people paid in Fureai Kippu over those paid in yen. This may be due to the personal connection. When they surveyed the elderly, it was clear they preferred the people who worked for Fureai kippu over the people who worked for yen because of the nature of the relationship. To convert this community service to yen would seem to dilute the community ethic. There are two clearinghouses that send the credits from one side of Japan to the other. China, too, is starting to implement the Fureai kippu concept.

Why it interests us:

The Fureai Kippu system has some how captured what it means to care and has created a strong community ethic, with a preference for these services over paid services. The fact that many western governments are struggling to understand how they can fund the care of the growing number of older people, makes this scheme all the more pertinent.

Find out more: http://en.wikipedia.org/wiki/Fureai kippu

Senior Co-Housing, Netherlands / UK Cohousing Network

Cohousing is a way of living, which brings individuals together in groups to share common aims and activities while also enjoying their own self-contained accommodation and personal space. Cohousing has taken off as a model for living in later life in the Netherlands, US and Denmark and can improve older peoples' lives by reducing isolation, encouraging active contribution to a community, developing new interests, pooling service budgets and encouraging peer support. There are currently several successful cohousing communities in the UK but as yet it has failed to be adopted as a model of living in later life despite strong interest from older people and government. The UK Co-housing Network is developing and testing a service that looks to link up interested older people and co-housing groups with developers, helping to overcome some of the barriers that currently exist for interested groups to make their cohousing development a

reality. The service will comprise a network service for older people, matchmaking them with developers who are interested in this area.

Why it interests us:

Cohousing is an interesting model as it has the potential to improve older peoples' lives by reducing isolation, encouraging active contribution to a community, developing new interests, pooling service budgets and encouraging peer support.

Find out more: http://www.cohousing.org.uk/

Southwark Circle, UK

The Southwark Circle community believes that people can be each other's solution, and backs it up every day, week and month by helping each other out with life's practical_bits and pieces. Southwark Circle is also about learning new things, and enjoying your hobbies and interests with others in the community. Southwark Circle was co-designed and tested with over 250 older people and their families, and developed by Participle. It was launched in May of 2009 and is a membership organisation reliant on the commitment and involvement of members and helpers. Begun as a pilot in the London borough of Southwark, the concept is now being rolled out across the UK. Southwark Circle is a social enterprise registered in the UK as a Community Interest Company (CIC).

Why it interests us:

Southwark Circle is interesting as it an innovative programme of social services for elderly people. It augments existing social care by creating local "circles" of support that combine concierge-style phone and internet help services with volunteer "neighbourhood helpers".

Find out more: http://www.southwarkcircle.org.uk/

The Good Gym, UK

The Good Gym pairs runners with isolated less-mobile people in their area. Runners jog to their house, deliver something nice, have a brief chat and are on their way again. It helps people get fit by providing a good reason to go for a run and it helps the person being visited by providing them with some friendly human contact and a newspaper or piece of fruit. Timing is up to the runner and the person they're visiting. Usually after work and weekends work best. Runners have to commit to at least one run per week. The Good Gym finds someone in the runner's area, gives them some advice and running tips and a list of phone numbers to call in case they need help. They will then be introduced to the person they will run to and can then get going. The Good Gym check in with both parties from time to time to make sure it's all going

smoothly. The Good Gym is currently running in Tower Hamlets, before launching a version that can be used more broadly.

Why it interests us:

By pairing joggers with isolated elderly people, the Good Gym innovatively repurposes something that runners are doing anyway to the benefit of those who are isolated at home.

Find out more: http://www.thegoodgym.org/

Aconchego, Portugal

Started in Porto, the Aconchego programme finds elderly people at risk of loneliness and isolation but with a spare room to offer, and matches them with local university students in need of inexpensive housing. The project now operates in Lisbon and Coimbra, while a similar programme, called Ensemble2Generations, is up and running in Paris.

Why it interests us:

Aconchego is interesting as it matches the need for student accommodation with the need to support older people living alone to the benefit of both parties.

<u>Find out more: http://www.euclidnetwork.eu/data/files/SocialInnovation/editaconchego.pdf</u>

Tyze, Canada

Tyze is an online social network site that offers personal, private, secure, online networks that help people to connect, care and contribute. Tyze users include:

- Adult children caring for their aging parents;
- People experiencing acute or chronic illness;
- Families supporting a member with a disability;
- Individuals facing a life challenge;
- Professional care providers seeking to provide coordinated care;
- People seeking to enrich their connections with family and friends.

The user includes their professional and personal carers and those who are interested/involved in their well-being. The aim is to provide a channel through which the user can feel empowered, supported and confident to live as mobile a life as possible. By being part of a network, the user has instant access to the people who can help them most, and those in the network can keep up to date and help the user. More specifically, Tyze can help the user and his network schedule appointments, discuss the user's goals, relate

stories about the user to each other, and provide information which will generally support them. By including those who form part of the user's formal and informal care systems, Tyze provides a holistic care service, utilising everyone's expertise efficiently and co- operatively. The user signs up, pays an annual fee (currently \$129) and invites those in his network to join. Network numbers are unlimited. The service also offers a private section on the network, for more confidential storage of data and discussions (limited to those people/ organisations whom the user gives access to).

Why it interests us:

Tyze is interesting as it demonstrates that social connections and mobility can be enhanced through online support.

Find out more: http://www.tyze.com/

Norcs, USA

Norcs, or "naturally occurring retirement communities", are buildings or neighbourhoods that have been retro-fitted to provide services for elderly people. Often located in a single residential estate or tower block, a Norc will provide traditional health and social care services (such as a live-in nurse or doctor) along with help with transport, education and recreation.

Why it interests us:

There are all sorts of norcs, that have evolved in different ways with different services, they are interesting as they demonstrate how communities can evolve to provide and develop services to support themselves.

Find out more: http://en.wikipedia.org/wiki/ Naturally occurring retirement community

Experience Corps, US

Established in the mid-1990s, Experience Corps has grown to become America's largest non-profit national service organization. In 20 cities across the country, 2,000 Experience Corps members tutor and mentor elementary school students. Experience Corps members are typically over 55, though some current members range in age from late 40s to early 90s.

Experience Corps members work in public schools and community centers tutoring and mentoring, providing homework help, and giving attention to those children most in need. In addition, members work with teachers, school leaders and youth workers to develop projects, such as parent involvement campaigns, health awareness activities and library book drives, which benefit entire schools and neighborhoods.

Research suggests that the programme helps its students boost their reading comprehension, while also improving the cognitive function of the elderly tutors themselves.

Why it interests us:

Experience Corps is interesting as it brings two groups of people together who have needs that can be met by working together – students are given support with their education and older people are given an opportunity to share their skills, work with the younger generation and keep connected to their community.

Find out more: http://www.experiencecorps.org

Bluelight

Bluelight is an iPhone app that notifies your friends and family when you don't arrive at your destination as planned. It was launched in January 2011 and can be downloaded free from Apple's App Store. Bluelight can be used whenever you're travelling from Point A to Point B and want someone to be notified if you don't arrive when you thought you would. Examples of when you might want to use Bluelight might be if you were meeting someone on a blind date, taking an early morning jog or going hiking or mountain biking.

Bluelight users begin by telling the app how much time they need to get to their destination on a particular occasion, such as a late-night trip home. They also designate a friend or family member for the application to contact if it's necessary. If they arrive at their destination as planned, they check in with Bluelight and their contact won't be bothered. If they don't check in, Bluelight will send a text message or email to the contact with the user's most recent location in the form of GPS coordinates plotted on a map. That person can then contact the Bluelight user to make sure everything is OK. Before using Bluelight it's recommended that users make a make a safety plan with the people who will be their Bluelight contacts.

Why it interests us:

Technologies like BlueLight have the potential to support people with dementia and alert carers should the need arise.

Find out more: http://www.bluelightapp.com/

De Verzilvering Project in the City of Almere, Amsterdam

De Verzilvering, is aimed at increasing the participation of older citizens, starting by making it easier for them to share a passion, such as music or keeping fit. It is part of Cisco's global Ageing Well programme, which is addressing two of the world's most significant and positive trends: the fact that people are living longer, healthier and more-active lives, and the potential for communication technologies to transform how people work, live, play and

learn. The project is being led by the Municipality of Almere and is supported by Cisco's global consultancy, the Internet Business Solutions Group (IBSG).

As part of the project, different video-enabled approaches will be experimented with, including live interaction, using the advanced video collaboration technology Cisco TelePresence, and timely use of video recordings through Cisco's easy-to-use high-definition video camcorder, Flip VideoTM. Live video pilots include enabling a fitness instructor to lead two groups of participants in different locations at the same time. Another will allow music lovers in different parts of the city to share their passion via Cisco TelePresence, where cross-city travel is not practical.

A hook-up with kindred spirits in Australia is already in the pipeline, and other natural extensions are being investigated, such as enabling more age-friendly work or volunteering. Recorded video is being used in inventive ways. Flip Video recordings are enabling choir members to feel included when they are not able to attend practice sessions. Pilot volunteers are using it to capture personal insights and to promote services and their impact across the city and beyond. Future plans include physicians, patients and families working together using Flip cameras to monitor medical symptoms, share support and advice, and increase the efficiency and efficacy of treatment.

Why it interests us:

The project is of interest as it aims to discover desirable and scalable new services that add value for the increasing ranks of older citizens, bring new opportunities for community providers, and promote self-sufficient communities that increase the city's attractiveness to citizens and investors alike.

<u>Find out more: http://www.cisco.com/web/about/ac79/docs/ps/Ageing-Well-in-the Netherlands Success Story IBSG.pdf</u>