



# Innovate Dementia



Shaping the future for people living with dementia

# Baseline Report



Innovate Dementia

[www.innovatedementia.eu](http://www.innovatedementia.eu)





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# INNOVATE DEMENTIA

## BASELINE REPORT

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## Baseline report: Innovative Dementia Care Solutions

### Introduction and background

Population ageing and the increased prevalence in long term conditions is a significant socio-economic challenge to North West Europe (NWE). It is economically unsustainable for us to maintain the status quo in terms of service delivery and provision. We are now at a time when transnational co-operation is necessary in order to find innovative ways to improve our knowledge of dementia and promote the exchange of information to preserve health, quality of life, autonomy and dignity of people living with dementia, including families and carers (ALCOVE, 2012, European Union 2010)

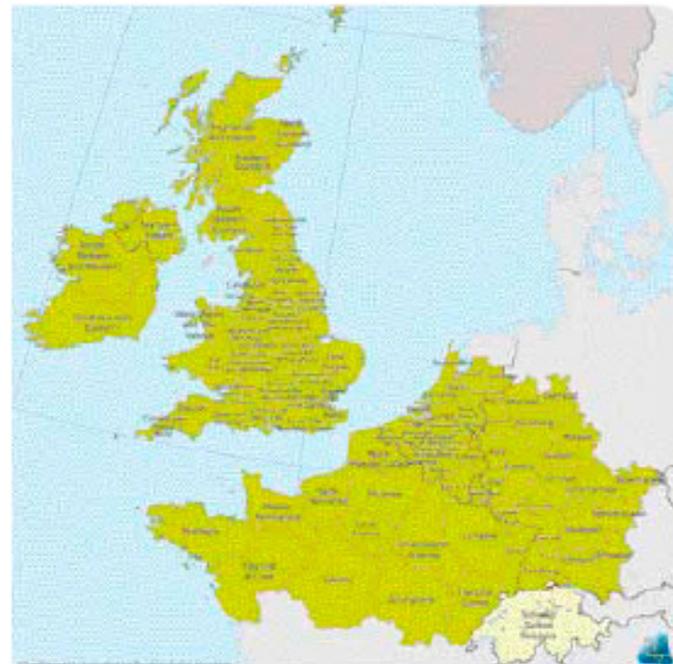
As a consequence of people living longer, current trends predict that the incidence of people with dementia will increase. Dementia is a long term condition that affects cognitive functioning, emotional control, mood, social behaviour and activities of daily living, beyond that what might be expected from normal aging. There are currently 35.6 million people worldwide living with Dementia and this number is expected to double by 2030 and more than triple by 2050 (WHO 2012).

Along with the growing recognition of the increasing number of people living with dementia and the socio-economic impact this will have upon societies in the imminent future, innovative approaches to care delivery are now essential to embrace the changes needed to health and social care planning and delivery. Living with dementia can be overwhelming and can significantly impact upon the quality of life of the individual, their families and carers. Until recently dementia has been known as a 'hidden illness'. However, the growing recognition has increased the urgency to find solutions that enable timely access to information, advice, and support and a pathway of effective intervention and care from the time of diagnosis to end of life care (Prince et al. 2011).

The need to take concerted action and develop innovative and cost effective dementia care provision, driven by the potential socio-economic threat to North West Europe, has inspired new ways of thinking and solutions that increase innovation and technologies. It has emerged as a key priority trans-nationally and nationally for governments, service providers and commissioners to improve the quality of care outcomes for people living with dementia and their carers (Department of Health 2011) with a number of European countries now with their own national dementia strategies

North West Europe, which includes Belgium, Netherlands, Germany, United Kingdom is one of the most dynamic and prosperous areas of Europe (table 1). It offers strong territorial assets as opportunities for shared developments and joint interventions, as it often experiences common environmental, social and economic pressures.

Table 1



**Structural Funds 2007-2013:  
Transnational Cooperation areas, North West Europe**

- Cooperation areas
- Other cooperation areas

The European Union funds projects, through the INTERREG IVB NWE Programme, in order to facilitate joint developments and interventions that

capitalize on opportunities to transform common pressures into opportunities for change, through transnational cooperation and strong partnerships. Innovate Dementia is one such funded programme (European Commission 2010).

Innovate Dementia is a transnational three year programme designed to accelerate and enhance NW Europe's capacity to innovate, through facilitating the development and sharing of knowledge based approaches and best practices for people living with Dementia. The programme aims to develop innovative, transferable dementia care models by exploring how technology and innovation can develop products and ways of living that will improve quality of life for people living with dementia and their families.

**Innovate Dementia aims to:**

- + Evaluate how innovative approaches in dementia care are utilised NW Europe, highlight best practice and future areas of research and development
- + Create collaborations which bring people living with Dementia together with health and social care, academic and business. Defined as a 'triple Helix' approach: to share and enhance each others knowledge, expertise and performance.
- + Influence the development of health innovation, new technologies and lifestyles to prevent the development of dementia and enable people to live well with dementia
- + Establish 'living labs' in order to test and evaluative innovative dementia care models, focusing specifically on key elements of integrated care:
  - + Intelligent Lightning,
  - + Nutrition and exercise,
  - + Living environment with social and

aesthetic conditions

- + Models of assistance for persons with dementia and their carers
- + Establish a solid framework for business collaboration and employment opportunities, linked with innovation, market need and regional, national European policy agendas

The 'triple helix' approach, which underpins the principles of Innovate Dementia, seeks to strengthen partnerships and collaborative working between Government/health and social care, Business and academia to enhance each other performance and improve the quality of care outcomes. This strengthened triple helix cooperation at regional, national and transnational level between all the Innovate Dementia partners creates opportunities to develop, implement and integrate innovative, long-lasting solutions to the socio-economic challenges linked with ageing and dementia.

It is fundamental to Innovate Dementia's sustainability and person-centred values that the triple-helix approach cannot work in isolation. It is vital that people living with dementia, who also want improved care outcomes, are central in the triple-helix approach and equal partners in the innovation process to 'co-create' and validate products and service development (Richardson & Cotton, 2011; Department of Health, 2011). The success of innovative solutions, new products and service developments are highly dependent on the triple helix partnerships engagement with and consideration of the needs and opinions of potential users and consumers, people living with dementia (Weber 2011).



## Report structure

The aims of the baseline report are:

1. To establish how innovative approaches in dementia care are being developed across all regions
2. To provide a knowledge platform and benchmark for the project's implementation plan.

**The report will be divided into three sections.**

### **Section 1: Scoping the problem: Global and regional dementia overview**

This section will help to define the vision and objectives of the Innovate Dementia project, it will include an evaluation of population needs, current health, social and community systems and services and identification of gaps in these areas

This section will include an analysis of:

- The national/regional demographic information
- Innovate Dementia profiles and impact
- Current service provision

Project validation

### **Section 2: Identifying priority areas for action: 4 key Innovate Dementia themes**

A review of the literature will be undertaken to establish a baseline of the innovate technologies utilised throughout north-west Europe in the delivery of care for people living with dementia. Specifically the baseline report aims to collect and analyse information related to the following four areas:

- + Intelligent Lighting,
- + Nutrition and exercise,
- + Living environment with social and aesthetic conditions,
- + Models of assistance for persons with dementia and their carers

## Section 3: Recommendation:

This section will explore the benefits for care users, home carers, the overall health economy and innovative business

- + Implementation of the plan
- + Committing resources
- + Inter-sectorial collaboration
- + Developing a time frame and a monitoring and evaluation system

The report sub-headings reflect guidance recommended in the WHO's Dementia: A public Health Priority report (WHO 2012). WHO make key recommendations to ensure a report is constructed which firmly addresses the needs on people living with dementia in an effective and sustainable manner.

The baseline report has been produced in collaboration with all Innovate Dementia partners.



## Section one

### ❖ Defining Dementia

*Dementia is a syndrome due to disease of the brain – usually of a chronic or progressive nature – in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in a large number of conditions primarily or secondarily affecting the brain (World Health Organization, 1993b: 46)*

Dementia, by its nature, does not lend itself to a clear and sequential pathway; people are affected in very different ways (NCCMH 2007). The term dementia defines a group of syndromes characterised by a progressive decline in memory, evident in learning new information and previously learned information and a decline in other cognitive abilities, such as judgement, thinking, planning, organizing and information processing (WHO 1993).

There are a number of different types of dementia, all with distinct symptom patterns and distinguishing microscopic brain abnormalities. The most common cause of dementia in Europe is Alzheimer's disease which accounts for around 50-70% of people diagnosed with dementia (European Commission 2009a), other common types of Dementia are:

- + vascular dementia – also known as multi-infarct or post-stroke dementia or vascular cognitive impairment,
- + Mixed dementia
- + Lewy Body dementia
- + dementia in other disease – such as

Picks disease, Creutzfeldt-Jakob disease, Huntington's disease, Parkinson's disease

Evidence from Long-term epidemiological observation and autopsy studies suggests that classification can be difficult in dementia as many people have microscopic brain abnormalities associated with more than one type of dementia, symptoms of different types of dementia overlap and in addition symptoms can be further complicated by coexisting medical conditions. Table 1 provides information (Alzheimer's Association US 2009).

As a society we have previously managed dementia by symptom control, however positively, the focus has now shifted to increase the value of preventative strategies and improving quality of life and wellbeing for those living with dementia. Person centred care is important in order to understand the individual's experience of dementia and to offer support and interventions that can improve a person's quality of life, overall wellbeing and ability to function as independently as possible in real life, everyday situations (Kitwood 1997, Woods 2004).

The psychological, emotional and social impact that dementia has on an individual, their family and carers is profound and the direct and indirect health, human and social care cost is considerable, this includes:

- + Direct medical and non-medical monetary costs such as medication, nursing/medical interventions, formal care and transportation
- + Indirect monetary costs such as loss of productivity, loss of earnings and withdrawal from the workforce by carers and family members
- + Health and wellbeing costs due to delays in accurate and timely diagnoses leading to delays in support and treatment

- + Health and wellbeing costs due to limited information and support to families and carers, caring responsibilities leading to financial hardship, social isolation and mental and physical health problems;
- + Unplanned monetary and wellbeing costs from emergency admissions (short-term or long-term) following breakdown of unpaid or unsuitable care (Alzheimer Europe 2008, The International Longevity Centre – UK 2011).

With this in mind, a starting position to take concerted action and develop innovative and cost effective dementia care provision is the recognition that across North West Europe, many current models of care do not offer the best approach for people living with dementia and current care provision is unsustainable in the long term.

Innovate Dementia's North West European partnership (Netherlands, UK and Germany) aims to accelerate and enhance North West Europe's capacity to innovate and develop cost effective models of care for people living with dementia. The transnational partnership provides the opportunity for strong cooperation, sharing of collective knowledge, best practices and development costs, all of which are invaluable when focusing on common environmental, social and economic pressures and considerably more effective than each country seeking solutions in isolation.

Key aims of the project are:

- + Evaluate how innovative approaches in dementia care are utilised in NW Europe, highlight best practice and future areas of research and development
- + Create collaborations which bring people living with Dementia together with health and social care, academic and business. Defined as a 'triple Helix' approach: to enhance each other's knowledge, skill and performance.

- + Influence the development of health innovation, new technologies and lifestyles to prevent the development of dementia and enable people to live well with dementia
- + Establish 'living labs' in order to test and evaluate innovative dementia care models
- + Establish a framework for business collaboration and employment opportunities, linked with regional, national and European policy agendas

### ❖ Demographic information

Population aging is increasing rapidly, it is predicted that by 2050 people aged over 60 will account for 22% of the world's population, compared to current figures of 8%. As a result this will significantly increase the number of individuals living with dementia (WHO 2012). Globally it was estimated that in 2011 35.6 million people were living with dementia, however it is estimated that this figure will significantly rise every 20 years, to 65.7 million in 2030 and 115.4 million in 2050, with a 40% increase specifically for Europe (Alzheimer's Disease International 2009).

The risk of dementia increases with age and the proportion of the population considered to have severe dementia significantly increases with age. Although reporting and comparing prevalence rates across countries is difficult due to variations in data methods, Ferri et al. (2005) reported that in Western Europe and the UK the prevalence of dementia was estimated at 0.9% of people aged 60–64, 1.5% aged 65–69, 3.6% aged 70–74, 6.0% aged 75–79, 12.2% aged 80–84) and 24.9% for people aged 85 and above. In addition, the prevalence of dementia increases for certain groups of people including people with Down's syndrome, learning disabilities, Parkinson's disease or who have had a stroke.

Dementia is one of the main causes of disability in later life. In 2011 the United Nations summit recognised that mental and neurological disorders,

including dementia, were a significant cause of morbidity, contributing to the global non-communicable disease burden. Their 'political declaration' emphasised the social and economic impact of non-communicable diseases on countries and the responsibility of governments at a global, regional and national level to engage all sectors of society to generate equitable effective access to programmes and health care interventions that support people living with dementia (United Nations 2011).

Dementia can affect anyone in our society irrespective of socioeconomic status, gender and ethnic background. There is limited current evidence in this area, however the evidence does suggest that there is lower awareness, higher levels of stigma and a different cultural understanding of dementia. Incidents of dementia are expected to rise more sharply in BME people (DOH 2009), however these differences may result in people presenting later to general dementia services than the white British population, when their dementia has become more severe (Mukadam 2010). Tailoring dementia care services to ethnically diverse populations is important to improve access and quality of support and information. However despite the recognition of the increasing number of BME people with dementia due to a steady increase in people within this age range, there is limited research looking at their needs and preferences and evaluating how well health and social care services are attempting to meet them (Moriarty et al. 2011).

Worldwide it is estimated that in 2010 the economic cost of dementia amounted to 381GBP / 453 EUR billion per year, reflecting the direct and indirect cost such as health and social care provision and loss of income for people diagnosed with dementia and their carers (Wimo and Prince 2010, WHO 2012). Specifically within Europe (27 member states) the European Commission (2009) estimated that dementia costs the EU 109GBP /

130 EUR billion a year based on direct and indirect costs, In which Wimo et al (2010) using cost-of-illness studies, estimated that the direct costs of dementia, including only the resources used to care for people with dementia totalled on average 0.5% of the Gross Domestic Product of countries among EU member states.

## ❖ Profiles: Innovate Dementia partners

In Western Europe, which represents Innovate Dementia regions, it was estimated that in 2010 the population aged over 60 years was 97.27 million with an estimated prevalence of dementia at 7.2% (6.98million). This figure is predicted to rise to 10.3 million by 2030 and to 13.44 million by 2050 (WHO 2012).

Alzheimer's Europe (2009) found that noticeable symptoms of dementia usually began and were reported after the age of 60 and reflecting worldwide statistics, the prevalence increased markedly with age, with more women than men diagnosed with dementia as women tend to live longer. In Europe, 14% of men and 16% of women aged 80-84 years were estimated as having dementia in 2009, compared to less than 4% among those 75 years of age and under. In people aged over 90 years the figure rises to 31% of men and 47% of women. Early onset dementia among people under the age of 65 years is much more uncommon, with less than 2% of the total number of people with dementia, although being mindful that this figure of people increased to 6.1 % in BME populations aged under 65 years (Knapp and Prince 2009).

## + The Impact of dementia

### UK overview

The UK population is approximately 62.3 million (ONS 2011) and as reflected globally the UK population is ageing. Between 2010 and 2051, the overall population is expected to increase to 78.7



million, whilst the proportion of people aged 65 and over is projected to rise from 17 to 24% and from 2 to 7% in the proportion aged 85 and over (ONS 2012).

There are approximately 700,000 people aged over 65 years diagnosed with dementia in the UK. This figure is expected to double to 1.4 million over the next 30 years (Knapp et al. 2007). In addition, although dementia is predominantly a disorder of older age, there are at least 15,000 people under the age of 65 who also have a diagnosis of Dementia (DOH 2009). Interestingly though a recent study by the Alzheimer's Society (2013) found that only 46% of people with dementia have a formal diagnosis, therefore the numbers estimated above are likely to be much higher than this.

Dementia costs the UK economy £20 billion each year (Alzheimer's Society, 2012), though over the next 30 years, the cost is predicted to treble to over £50 billion per year (Comas-Herrera et al. 2007). An Alzheimer's Research Trust study reported that the cost of £20 billion per year to the UK economy is significant compared to the £12 billion per year spent on cancer and £8 billion per year on heart disease. However conversely, dementia research investment is low compared to other disease groups and by international standards (Luengo-Fernande et al. 2010).

Currently two thirds of all people with dementia live in their own homes with an estimated 670,000 people in the UK acting as the primary carers for people with dementia (Alzheimer's Society, 2012). One third of people with dementia reside in care homes. Dementia is now the strongest determinant for admission into care homes, two thirds of all residents (Alzheimer's Society 2007) and people with dementia are currently occupy up to a quarter of hospital beds at any one time (Alzheimer's Society 2009).

## Netherlands overview

The overall population of the Netherlands is 16.795.650 people (Statistics Netherlands 2012). In 2012 there were more than 250.000 people living with dementia and in 2050 this number is expected to rise to 564.000 (Alzheimer Netherland 2012).

In 2011 the direct and indirect costs related to dementia were 3.9 billion euros, almost 5% of the total health costs in the Netherlands. This cost is expected to increase to more than 6 billion euros in 2028, confirming that dementia will be the most expensive disease in the Netherlands (Alzheimer Netherland 2012). Until recently the Netherlands government has financial responsibility for the overall healthcare management in the Netherlands. However, in the new governmental healthcare plans for 2013, healthcare financial responsibilities will be more managed locally, by the different communities. This change will mean that a community, for example Eindhoven, will be responsible for managing and financing support plans (domestic help, volunteers), additional care (optimal social environments) and (integrated care management for people living with dementia in their region).

In the Netherlands 70% of people with dementia still live at home, whilst 30% live in supported accommodation, such as nursing homes, retirement homes, sheltered housing. Whilst at home most care is provided by informal carers (60%), such as relatives, whilst 75% of people living with dementia need additional daily care or supervision and 15% need 24 hours care and supervision (TNO innovation for life, 2011).

## Germany overview

The population of Germany is approximately 81.8 million and as reflected globally the number of older adults is increasing to 16.8 million. 20.5% of adults are currently aged 65 years and older and this is predicted to rise to approximately 32-34% or 21.9 million by 2060, dependent upon birth rate



and several other factors (Statistisches Bundesamt 2012).

This rise in older adults has led to an increase in a number of people with physical and mental illnesses, including dementia. 7-8% of the population aged 65 and older are affected by dementia (Jorm et al. 1987), which in 2012 equates to 1.4 million people. This figure is predicted to increase, resulting in 1.8 million people living with dementia by 2060. In contrast to the increasing percentage of older adults, the number of informal carers will decrease, resulting in care services in the future spending a higher proportion of their GDP on care.

80% of people with dementia in Germany receive care at home. When care takes place at home, the costs per person per year is estimated as 47000 € per year, whereas the mean predicted cost for care in a retirement home can be estimated as 36000 € per year. In addition, regardless of setting additional medical treatment costs are estimated as 14000 € per person, per year, thus for institutional care, the total estimated costs are 50000 € per person and year (IDA, The initiative Dementia Care in general practice 2010).

### ❖ Service provision

Although there is only minimal variation in prevalence rates for dementia across North West Europe, there are greater variations in the health and social care systems in each country. Each country tends to:

- + identify and diagnose dementia differently
- + identify and assess need in a different way
- + Dedicate variable amounts of resources to meet the needs of people living with dementia
- + Provide a range of ways to deliver treatment and support through both formal services and reliance of family and carer support (Knapp et al. 2007).

Following the commitment to respond more effectively to dementia and its impact on individuals, care givers, governments and societies, there has been a number of global, transnational and national dementia plans introduced to improve health and social care provision and change the experience of living with dementia.

On a global level the World Health organisation and Alzheimer's Disease International launched Dementia: a public health priority in 2012. Its aim to raise awareness of dementia as a public health priority and to advocate for action from governments, policy-makers, and other stakeholders at international and national level to address the impact of dementia. (WHO 2012). This was reflected on a European level in 2008 during the France's President's EU presidency when he held a convention calling on all member states to prioritise dementia. The White Paper Together for Health: A Strategic Approach for the EU 2008-2013 outlined the EU Health Strategy concerted commitment to a better understanding of neurodegenerative diseases such as Alzheimer's in context of demographic ageing. The commitment emphasised that it would support national efforts in four key areas of dementia: 1) prevention: including measures to promote mental well-being, 2) early diagnosis and coordinating research across Europe, 3) sharing best practice for treatment and care and 4) developing a common approach to ethical questions – rights, autonomy, and dignity of people with dementia.

On a national level:

### UK

The National Dementia Strategy for England (2009) aims to drive an equitable health and social care systems for all people living with dementia. The strategy has three goals; to encourage help-seeking and help-offering by changing public and professional attitudes, understanding and



behaviour; to make early diagnosis and treatment the rule rather than the exception and to enable people with dementia and their carers to live well with dementia the provision of good-quality care for all with dementia from diagnosis to the end of life regardless of setting. Following this the National Dementia Vision for Wales (Welsh Government, 2011) was launched which prioritised early diagnosis and timely intervention, Scotland's National Dementia Strategy (Scottish Government, 2010) which strengthened the need for support and information for people with dementia and their carers and the Ireland Dementia strategy (DHSSPS, 2011) which reiterated the need for earlier diagnosis and multidisciplinary assessment

Building on the National Dementia Strategies, in 2012 the Prime Minister launched the Prime Minister's challenge on dementia: Delivering major improvements in dementia care and research by 2015. The challenge on dementia is an ambitious programme of work designed to make a real difference to the lives of people with dementia and their families and carers. The challenge is to the whole of society as well as government and will focus on three key areas; driving improvements in health and care, creating dementia friendly communities that understand how to help and better research

### Netherlands

An important public health initiative and key driver in the Netherlands is the "Zorgstandaard Dementie" (Vilans and Alzheimer Nederland, 2012). It is the national care standard for people living with dementia, published by 30 health organisations in the Netherlands and supported by the government (Ministerie van Volksgezondheid, Welzijn en Sport). The document encompasses the most optimal care system from different perspectives, such as early detection, prevention, diagnosis, case management, treatment, counselling and support, care and services.

National guidelines and standards for diagnose and treatment of dementia (CBO Guideline 2005, NHG-Standard M21, 2012, Verenso, 2009) by quality institutes and joint associations of the Netherlands have been developed. Diagnosis of dementia is based on clinical research on multiple cognitive disturbances and whether these symptoms fit into the criteria of the National Institute of Neurological and Communicative Diseases and the Alzheimer's Disease and Related Disorder Association (CBO Guideline 2005).

### Germany

In 2002 the 4<sup>th</sup> Report on Ageing of the German Government was published. This described the situation of people with dementia in Germany and included recommendations how to proceed politically. Several structural initiatives were taken. The government associated "Aktion psychisch Kranke e. V." received the task to develop models of future caring structures for the elderly with a special focus on dementia. Several initiatives were started by ministries (for example "Leuchtturmprojekte" on service structures in dementia). In 2008 early diagnosis of neurodegenerative diseases, including Alzheimer's disease was defined as one of the six priority areas of the German Federal Ministry of Education and Research (BMBF). In addition, the German Helmholtz Centre for Neurodegenerative Diseases (DZNE) was established with an annual budget of € 66 million.

Overall common and shared elements of these reports and national policy drivers include:

- + the need for a coordinated multisectoral approach;
- + the need to provide accessible, affordable and good quality health and social care and services that meet the needs and expectations of people with dementia and their families;
- + and the importance of ethical, social, legal



and financial protection, avoid become over-dependent on costly institutional care (WHO 2012).

## ❖ Validation

Validation of the ways in which technology and innovation can develop products and ways of living that will improve the quality of life for people living with dementia and their families will be sought in a number of ways:

**A triple helix approach** to innovation, which is when Government/health and social care, Business and academia work in partnership to co-innovate and solve shared socio-economic challenges, will be used throughout the life of the Innovate Dementia project. A triple helix approach is ingenious as it draws of the expertise, skills and knowledge of all tripartite partners to work collaboratively to enhance each other performance through the process of communication, design, planning, investment, implementation and evaluation. An additional strength of the Innovate Dementia project is that the triple helix cooperation will progress at a regional, national and transnational level, through the cooperation of all partners.

**A person centred approach** to innovation is fundamental to Innovate Dementia to ensure that people living with dementia, who also want improved care outcomes, are central in the triple-helix approach (or possible quadruple-helix approach) and are equal partners in the innovation process to 'co-create' and validate products and service development (Richardson & Cotton, 2011; Department of Health, 2011). The success and validation of innovative solutions, products and service developments are highly dependent on the triple helix partnership listening to and engaging with people living with dementia (Weber 2011), as the most successful technologies are the ones that 'fit' with the real needs of the person with dementia (Dewsbury & Linskill, 2011). The principle of co-

design and co-creation helps to generate innovative ideas which will result in positive changes for both service users and staff (The King's Fund 2012a). The approach draws on the skills, knowledge, time and expertise of service users, and regards the relationship between professional and service user as a meeting of two experts, challenging the perception of service users as passive recipients of care (Ham et al. 2012).

The European Commission (2009) asserted that insufficient consideration is often given to the rights of people living with dementia. There is a general lack of recognition of the mental capital of older people, limited knowledge and understanding of dementia and an associated stigma that can negatively influence involving people living with dementia in future developments and innovation. The principles of 'person-centred care' are fundamental to empower people living with dementia to influence dementia knowledge, expertise, help action planning and guide decision making.

Person centred care respects the importance of:

- Safeguarding the human value of people with dementia, regardless of age or cognitive impairment, and those who care for them
- Maintaining the individuality of people with dementia, with their unique personality and life experiences
- Hearing and understanding the perspective of the person with dementia
- Prioritising the importance of relationships and interactions with others and their potential to promote well-being (Kitwood 1997)

**A living lab approach** to innovation will facilitate the development and testing of new or existing technologies and innovative ways of living within the person's real life and natural living environment. The Innovate Dementia definition of a living lab is a 'pragmatic research environment which openly



engages all relevant partners with an emphasis on improving the real-life care of people living with dementia through the use of economically viable and sustainable innovations’.

A living lab is underpinned by the following principles:

- + **Continuity** - this needs to be apparent both in terms of product development and in terms of transnational working.
- + **Openness** – partner participation should be inclusive with a focus on user-driven innovation.
- + **Realism** – the innovation process should be shaped by real situations and behaviours
- + **Empowerment of users** – there should be a focus on empowering users to actively participate and shape the innovation process.
- + **Spontaneity** – users spontaneous ideas and views should be actively encouraged and explored.

Further to these principles Innovate Dementia have strengthened the ‘user-friendliness’ of this approach as it is recognised that if innovations really are to be accepted and implemented, they must reflect the needs and preferences of people living with dementia. It is important to understand that a living lab is a dynamic structure that will be utilised to explore, evaluate and validate potential innovations (including intelligent lighting systems, dietary/exercise programs, living environment or models of assistance for people living with dementia). The main goals of this approach are to:

1. Generate innovations for people living with dementia, by developing concepts that will support them to live longer in their own houses. Concepts are based and further developed through a user-led needs-assessment process.
2. Create sustainable living lab architecture for exploration, evaluation and validation of new innovative concepts.

3. Generate economic activity through strong collaboration between stakeholders (quadruple-helix) and develop innovative insights which have the potential to optimise dementia healthcare.



## Section 2

Within this section a review of innovative solutions and technologies that are being used to improve care outcomes in dementia will be undertaken. The review of literature will establish a baseline of innovate technologies utilised throughout north-west Europe in the delivery of care for people living with dementia. Specifically the baseline report aims to collect and analyse information related to the following four areas:

- + Intelligent Lighting,
- + Nutrition and exercise,
- + Living environment with social and aesthetic conditions,
- + Models of assistance for persons with dementia and their carers.

### ❖ Methodology

The responsible partner took the lead in the coordinating and compiling of the report, with engagement and feedback from all other partners. Partners systematically reviewed the literature related to the four areas discussed above from a national, trans-European and global level, which ensured that there was an appropriate coverage of relevant technologies during the literature review. The initial scope was intentionally broad to assist the identification of potentially useful references within the areas of:

- + Lighting
- + Exercise
- + Nutrition
- + Environmental / living conditions
- + model of access to assistance/consultation for patients and carers.

However, the literature searches were also shaped by considering such factors as;

- + national/regional opportunities and barriers
- + analyse existing dementia care models

- + best practices
- + legal/policy/financial frameworks
- + common opportunities to increase uptake/use of innovative, technology-based dementia care within Europe.

In order to focus on more recent literature, it was agreed that where appropriate to only use references produced during the last 15 years.



## Innovate Dementia theme: Intelligent Lighting

Distressing symptoms such as agitation and aggression can frequently occur in dementia and it is not uncommon for these symptoms to be to be worse at certain times of the day such as in the late afternoon to evening (sundowning phenomena) (Vardy & Robinson, 2011; Ballard et al., 2009; Ballard et al, 2008; Bachman & Rabins, 2006). It is not unusual for these symptoms to be managed through the use of pharmacological treatments, although due to the side-effects of these treatments there has been a move towards using non-pharmacological interventions (Snowden et al., 2003; Ballard et al., 2009; Ballard et al., 2008 Corey-Bloom et al., 2006; Douglas et al., 2004; Hogan et al., 2008; Eun-Hi Kong et al. 2009; Sadowsky & Galvin, 2012). The use of these interventions are in their early stages and it has to be acknowledged that there is a need for more rigorous research in this area (Baillon, 2002; Azermaia et al., 2012; Livingston et al., 2005).

In terms of non-pharmacological interventions, a key area of development is the use of light as a therapy, especially in relation to managing aggression and agitation, but also as a way of managing disordered sleep, which is another common symptom in dementia (Wolkove et al., 2007). It is important to note that insomnia is not uncommon among older people and also among other types of dementia such as Huntington's disease (Wolkove et al., 2007; Morton et al., 2005). A study by Turner and Mainster (2008) highlights that age related effects in the eye can negatively impact upon an older adult's 'circadian photoreception' and this in turn may negatively impact upon an individual's sleep-wake cycle. Turner and Mainster (2008) also make the point that poor environmental lighting can compound the problem especially as artificial

lighting is 'dimmer and less blueweighted than natural daylight' (pp.1439). A literature review by Torrington and Tregenza (2007) stresses this point in that lighting for people with dementia should take into consideration a person's exposure to sunlight within the day and night cycle. The findings from a systematic review by Dijkstra et al., (2006) to 'determine the effects of physical environmental stimuli in healthcare settings on the health and well-being of patients', supports this view by indicating that 'there were predominantly positive effects found for sunlight' (pp.166). Aarts et al. (2006: 47) also makes the point that there is a 'positive correlation between sleep efficiency and exposure duration to high intensity light, meaning that more light is related to efficient sleep'.

There is evidence of a neurological link to a disrupted circadian rhythm in dementia which centres on the roles of cortisol and melatonin levels (de Jonghe et al., 2010; Hanania & Kitain, 2002; Hatfield et al., 2004; Wirz-Justice, 2006; Riemersma, 2004). In terms of agitated behaviour seen in the sundowning phenomena, a study by de Jonghe et al., (2010) indicates that agitated behaviour seen in dementia can improve when treated with melatonin. On this basis it is postulated that sundowning behaviour is explicitly related to a disturbance of the circadian rhythm (de Jonghe et al., 2010). This concurs with Hanania and Kitain's (2002: 338) view that 'plasma melatonin levels play an important role in the regulation of the sleep-wake cycle'. This disruption has a cyclic effect in that circadian disruption in dementia can in turn exacerbate existing behavioural problems (Turner & Mainster, 2008). Further to this view a controlled trial by Mishima et al., (2001) links bright light with melatonin secretion levels, suggesting 'that we need to pay attention to older individuals who suffer under conditions of poor environmental light resulting in



disorganized circadian rhythms, including the sleep-wake cycle' (pp.129).

A study by Carvalho-Bos et al. (2007) suggests that interventions that increase daytime activity and the stability of the rest-activity rhythm may improve well-being. A review by Shirani and St. Louis (2009) takes this view one step further and concludes that based on circadian neurobiology that there is a role for light therapy in clinical practice. Terman and Terman (2005) also indicate that timed light exposure has some promise for the treatment of sleep disorders in dementia. Terman (2007) makes the specific point that 'the rest-activity disturbance of people with dementia has been partially allayed under light therapy'. Wirz-Justice (2006) and Skjerve et al. (2004) also indicate that there is some promise in using light therapy for with individuals with dementia, however based on the work of Kverno et al., (2009) it is important that any non-pharmacological approach is individually tailored.

In terms of research, light therapy as an intervention for agitated behaviour in dementia, like disordered sleep, is in its early days, studies by Thorpe et al. (2000), Burns et al. (2002), Ayalon et al. (2006) suggest that bright light therapy may be efficacious and a safe way to manage this type of behaviour, however they also highlight that further research is required. According to Dijkstra et al. (2006) there is also a need for more evidence based research, including the need for more randomised controlled trials. This view was echoed in a Cochrane review by Forbes et al., (2004) on 'bright light therapy (BLT) in managing sleep, behaviour, mood, and cognitive disturbances associated with dementia'. This study concluded that at the moment 'there is insufficient evidence to assess the value of BLT

for people with dementia' (pp.2). The Scottish Intercollegiate Guidelines Network (2006) guidance for managing people with dementia also suggests that 'Bright light therapy is not recommended for the treatment of cognitive impairment, sleep disturbance or agitation in people with dementia' (pp.10).

It has to be acknowledged that light therapy as an intervention for sleep disorders in dementia is a difficult area to research and on this basis Terman and Terman (2005) make the point: *"... although we are impressed by the research activity in this very difficult area, the key to effective treatment has been elusive. Factors of diagnostic heterogeneity, stage and severity of disease, circadian system status, ocular status, optimal timing of light treatment, and exposure parameters and duration of treatment still need to be sorted out."*

(Terman & Terman, 2005: 1437)

Further to 2006, a systematic literature review by Brown et al. (2011) suggests that light therapy of all the non-pharmacological interventions has more 'conclusive' evidence in reducing disorder sleep than other interventions. A study by Sloane et al., (2007:1524) using 'a cluster-unit crossover intervention trial involving four conditions: morning bright light, evening bright light, all-day bright light, and minimum standard light' on older adults with dementia; concluded that 'bright light appears to have a modest but measurable effect on sleep in this population, and ambient light may be preferable to stationary devices such as light boxes'.

Light therapy research for agitated type behaviours in dementia has also struggled to come to terms with the complex nature of this type of research. A study by Ancoli-Israel et al. (2003) observed a 'shift in the peak of agitated



behaviour' more so in mild dementia than severe dementia, though a randomised trial by Dowling et al. (2007) concluded that 'bright light therapy did not clinically affect neuropsychiatric behaviours' (pp.971). They also make the point that it was difficult to control such factors which may have impacted upon their findings such as not being clearly able to quantify agitated behaviour and also not being able to discount the impact of prescribed medication (Dowling et al., 2007).

A literature review by Montgomery and Dennis (2004) suggests: *"Evidence of the efficacy of bright light and exercise were so limited that no conclusions about them can be reached as yet; however, in view of the promising results of bright light therapy in other populations with problems of sleep timing, further research into its effectiveness with older adults would seem justifiable"*. (Montgomery & Dennis, 2004: 47)

It is useful to note that studies by Van Someren et al. (1997), Sloane et al. (2005) and Sloane et al. (2007) highlight the potential of high intensity light in the management of sleep problems and also restlessness behaviour in dementia. Further to this a study by Van Hoof et al. (2009) exploring the intensity of light in managing restlessness in dementia suggests that 'high-intensity bluish light may play a role in managing restless behaviour and improving circadian rhythmicity in institutionalised older adults with dementia' (pp.146).

Using light in a therapeutic sense is not just to confined to using light as a therapy, a study by Teresi et al., (2000: 417) highlights the 'environment is an area that is critical to specialized dementia care' which includes the use of lighting; Boyce (2003) specifically stresses the importance of lighting quality. Certainly Voermans et al. (2007: 158) highlights that

'falls in older people are a common, dangerous and frequently incapacitating problem'. Good environmental lighting as indicated by Chang (2004) can help to prevent falls, also it may potentially reduce aggression by helping people with dementia make sense of their environment (Hughes & Adams, 2012). Further to these studies articles by Doody et al. (2001) and Evans and Cotter (2008) stress the importance of 'environmental manipulation' such as using good lighting especially where falls can be prevented without the use of restraint, a common intervention in fall prevention.

It is important especially in today's climate of community care that light technologies have utility within the home, that they can be introduced by informal carers, and that they are holistic with an explicit relationship to a care package approach (Cook, 2012; Topo, 2009; Hulme et al., 2010; Carswell et al., 2009; Koch et al., 2006; Kolanowski & Whall, 2000; McCullagh et al., 2009; Prince et al., 2009). On this basis the effective management of dementia including using light technologies may delay the transition for home-based care to hospital/nursing home care, something future research will need to determine (Lawlor, 2002; Hulme et al., 2010). Where light technologies are used within institutional settings though there is a requirement to understand the generalised impact of these technologies there is also a need to understand these technologies at an individual level, the level where care is ultimately provided (Cutler & Kane, 2002). It is also important to note that the use of light technologies will create a potential training need, not just in terms of delivering this type of intervention, but also in terms of clinical decision-making; identifying when it should be used and when it should not (Mason & Adeshina, 2011; McGilton et al., 2007).





In conclusion there is promising evidence that light can be used as a therapy and as way of improving the environment for individuals with dementia, however there is need to consider the following;

- + More controlled trials are required, certainly within the area of symptom management, these trials need to consider such technical factors as the intensity, duration, spectral content, and method of exposure of the light therapy
- + Light therapy research has to be care-packaged focused, for example future research would not just consider the rest-wake cycle in isolation it would need to consider rest-wake activity cycle in conjunction with diet and exercise, and it would also have to consider the community-based nature of care delivery
- + Future research would have to consider lighting as a way of managing the environment; and it would need to consider any future training requirements in the use of lighting and light therapy including the development of specific assessment tools (Lawton, 1997).



## Innovate Dementia theme: Exercise

There is little robust evidence for the primary prevention of dementia, however theoretically the most promising is by reducing vascular risk. It is now understood that Alzheimer's Disease begins at least two decades before the earliest symptoms manifest, therefore to impact on disease development preventative strategies need to be aimed at people reaching their 40's and 50's. Despite this, interventions such as physical exercise still have a positive impact on people who have dementia by improving quality of life, physical health, affective symptoms and possibly influence the rate of decline (secondary and tertiary prevention).

The World Health Organisation (2010) describes physical activity as any bodily movement produced by skeletal muscles that requires energy expenditure. Physical activity is a term used to cover a range of different exercises such as walking, yoga, tai chi, cycling, stretching and toning, chair based multi-modal exercises etc. NICE (2008) fully endorses the importance of physical exercise as a means of promoting good health and preventing disease. The evidence suggests that currently aerobic exercise is more beneficial than stretching and toning type exercises. Forbes et al. (2008) state that there is more conclusive evidence around aerobic type of exercise which has clear benefits over resistance training. Colombe and Kramer (2003) and Lautenschlager (2008) describe the largest beneficial effects when aerobic exercise is multi modally combined with strength and flexibility components. There are large variations in content and intensity (Scarmeas 2011), frequency and length of interventions within the studies and some exercise programmes also involved using other modalities (Kemoun 2010). In terms of frequency some studies indicate three times a week (Abbot et al. 2004, Erickson 2010) as a benchmark whilst others define an active lifestyle as more than 1 hour physical activity per day. NICE Public health guidance recommends 30 minutes of

exercise at least 5 times per week (NICE 2008). There is also large variability in the length of interventions ranging from a 10 day period to a 24 week period (Lautenschlager 2008).

The benefits of exercise for health are well reported and widely accepted. WHO (2010) state that regular moderate intensity physical activity for example walking, cycling, or participating in sports has significant health benefits, such as reducing the risk of cardiovascular diseases, diabetes, colon and breast cancer, and depression. In addition adequate levels of physical activity will help control weight and decrease the risk of a hip or vertebral fracture.

More recently the impact of physical activity on cognitive processes has been considered. Foster et al. (2011) report that lifestyle factors including intellectual, cognitive and social stimulation, nutrition and various types of exercise appear to reduce the risk for common age related disorder, e.g. Alzheimer's Disease. Colombe (2006) reports that in the third decade the brain shows structural decline associated with deterioration in a range of cognitive processes. Erickson et al. (2010) describe how exercise training increases anterior hippocampal volume and therefore improves memory. The hippocampus shows more age related atrophy which can lead to problems with memory and risk of dementia. Studies have demonstrated that hippocampal and medial temporal lobe volumes are larger in fitter adults. This is associated with greater serum levels of BDNF, mediator of neurogenesis in the dentate gyrus. Physical activity increases hippocampal perfusion.

Pre intervention fitness partly attenuated the decline, suggesting fitness is protective against volume loss. Schuit et al. (2001) describe the positive effects of an active lifestyle and reported a more pronounced effect in those with ApoE4 allele. Erickson et al. (2010) investigated the extent to which aerobic exercise training can modify hippocampal volume in later life leading to improvements in spatial memory



and found that exercise training increased it by 2%, effectively reversing age related loss in volume by 1-2 years. Intlekofer and Cotman (2012) state that taken together, animal and human studies indicate that in advanced age and Alzheimer's disease, exercise can counterbalance the effect of molecular changes that triggers the progressive loss of hippocampal function.

Foster et al. (2011) detail the multiple complex processes and molecular mechanisms involved in the protective effect of exercise against cognitive deterioration with regard to exercise-induced entorhinal and hippocampal neuroplasticity, sarcopenia, biological mediators and growth factors and conclude that the effect of skeletal muscle exercise produces a maximal efficiency at the pre-symptomatic and prodromal stages.

It is important to consider the implications from studies of physical exercise carried out on healthy older people which describe positive effects on cognition. Studies by Abbot et al. (2004) and Hertzog et al. (2008) indicate that regular physical activity for example walking, cycling, hiking or swimming at least three times per week may reduce the risk or delay the onset of dementia. Scarmeas et al. (2011) found that physical exercise has been related to lower risk for Alzheimer's Disease; comparing participants who were physically inactive with those with some degree of physical activity had a lower mortality risk and those with higher physical activity levels had even lower risk. When compared with physically inactive subjects, those with some physical activity lived approximately 5.5 years longer and those with high levels of physical activity approximately 8 years. This appears to be related to reduced physical co-morbidities. In this study physical activity did not affect rates of cognitive function or decline.

Colcombe and Kramer (2003) report that physical fitness training improves cognition and executive function of healthy but sedentary older people and

in a further study demonstrated that physical fitness is associated with improvements in task related brain activity, attentional network and increases grey and white matter volume, therefore it may counteract normal age related loss of brain tissue and function. Structural preservation was greatest in the frontal and parietal regions associated with higher order attentional control and memory processes. Angevaren et al. (2008) considered physical exercise on physical health of older people which resulted in improvements to both physical and cognitive capacity, mainly auditory attention and information processing speed. Lautenschlager et al.'s (2006) study highlighted that healthy and physically active older adults show significantly better cognitive function and less cognitive decline echoed by Yaffe et al. (2001)'s study showing that participants with greater physical activity levels at baseline experienced less cognitive decline.

Forbes et al. (2008) reviewed physical activity programmes for people with dementia. In general, for healthy older people positive effects can be seen on improved cognition. This is seen in a study by Angevaren et al. (2008) where an aerobic exercise programme in healthy older adults reported improvement in at least one aspect of cognitive function, functional ability (Larowski 1999) and mental health. Most studies demonstrated that high levels of physical activity in older adults without dementia are associated with a 30-50% reduction in risk of cognitive decline and dementia (Barnes 2007). The review concluded that evidence was insufficient to attribute improvements in cognitive function to cardiovascular fitness although temporal association was strong. Brown et al. (2012) used actigraphy to measure association between intensity (not volume) of physical activity and cognitive function with cognitively healthy participants aged 60 years plus. Their findings indicated that participants with the highest physical activity intensity levels performed significantly better on a range of cognitive tasks



indicating intensity rather than quantity may be more important.

Considering work from non human studies may help to understand the impact of exercise on brain structure and volume particularly. In animal models (Garcia- Mesa 2011) exercise treatment ameliorated cognitive decline and behavioural and psychological symptoms of dementia (BPSD), synaptic changes were partially protected by exercise and improved neuro-protection was generally obtained after 6 months of exercise. The benefits of aerobic physical exercise on synapses, homeostasis and general brain function demonstrated in mice support the value of healthy life style against neuro-degeneration. Colombe et al. (2006) used previous work on non humans demonstrating that chronic aerobic exercise can lead to growth of new capillaries, increase length and number of nerve cell interconnectors and increase cell production in the hippocampus. Fitness correlates with brain volume and exercise and in non human models causes neurogenesis. There have been some attempts to establish the impact of physical activity on the risk and process of dementia. From work on non human studies Cotman et al. (2007) suggested that as well as the above, exercise reduced peripheral factors like diabetes, hypertension and cardiovascular disease and suggested that exercise may attenuate some of the cognitive symptoms and pathophysiology of dementia. Langdon and Corbett (2012) concluded that a combination of physical activity and cognitive stimulation improves learning and memory abilities independent of activity intensity. He suggests an adaptation of this approach may be particularly beneficial in slowing the development of mild cognitive impairment (MCI) and subsequent dementia.

Extrapolation from the studies of physical activity on healthy older people and non human studies is difficult due to methodological issues and large variations in exercise duration and frequency

however; the potential of physical activity to ameliorate the symptoms of dementia is an interesting area of research. Dementia is caused by structural changes within the brain with various disease processes causing death of brain cells. Impaired motor activity can lead to reduced levels of physical activity in people with dementia, therefore compromising the protective influences of physical activity.

Recently, moderate exercise and improved fitness have been shown to enhance cognition in cognitively intact older people as well as those with MCI. Yonas' (2010) study suggested that any frequency of moderate exercise performed in mid life or late life was associated with reduced odds of developing MCI. Alternatively it is also a marker for a healthy lifestyle. Rockwood and Middleton (2007) indicated that preliminary evidence suggests physical activity might affect risk of different types of dementia differently and that observational studies found preventative effects of exercise were weaker for vascular dementia than for Alzheimer's disease. Buchman et al. (2012) tested the hypothesis that an objective measure of total daily physical activity predicts the incident of Alzheimer's disease and cognitive decline. This study involved 716 older people and concluded that a higher level of daily activity is associated with a reduced rate of Alzheimer's disease. Winchester et al. (2012) studied the effects of walking for over 2 hours a week for one year on people with early stage Alzheimer's Disease. They found that the active group had a significant improvement in MMSE score over the sedentary group.

A study by Baker et al. (2010) in healthy older people with a diagnosis of mild cognitive impairment (MCI) showed that aerobic training improved executive function, attention and information processing speed. Similarly Lautenschlager et al. (2008) had found that in older adults at risk of developing dementia (i.e. subjective complaints regarding



memory, MCI or ApoE4 carriers) assigned to a 24 week physical fitness programme participants improved cognitive function by .26 on ADAS-Cog (Alzheimer's Disease Assessment Scale-cognitive subscale). A community based study by Vreugdentil et al. (2012) assessed the efficacy of a home exercise programme in people with impaired cognition (mild to moderate Alzheimer's Disease) after 4 months those who exercised had improved cognition (MMSE), better mobility and increased instrumental activities of daily living (ADL).Thurm et al. (2011) described a 10 week multi modal movement intervention to establish whether it could slow cognitive deterioration in people with dementia and physically very frail nursing home residents. Results demonstrated no further overall cognitive decline throughout the period and significant improvement on ADAS-Cog orientation/praxis sub scores. Kemoun (2010) results demonstrate significant improvements in overall cognitive function in older but physically well nursing home residents with moderate to severe dementia after 15 weeks of physical training with improved scores for orientation and praxis (ADAS-Cog) ,preservation of overall cognitive function whereas control group showed cognitive decline. Eggermont et al. (2008) study results did not support this finding.

It appears that some of the benefits of exercise programmes are in other areas not cognition directly, these are activities of daily living, physical health and behavioural and psychological symptoms of dementia. Rolland (2007) found that one hour twice a week exercise programme for one year showed significantly slower decline in abilities for activities of daily living. Eggermont et al. (2006) highlighted that for care home residents to show any benefits in activities of daily living there needs to be a long term exercise programme with extensive sessions.

Fan and Chen (2011) found that older people with dementia in long term care who participated

in a yoga programme had improved physical health (including lower blood pressure, reduced respiration rate, strengthened cardiopulmonary fitness ), also describing non specific improvements to mental health. Heyn et al. (2004) proposed that physical activity (walking or combined walking with isotonic training) may be able to reduce the risk and to decelerate the progression of neurodegenerative processes.

Heyn et al.'s (2004) study demonstrated no significant training effect however when data for functional, cognitive or behavioural outcomes was analysed they reported a significant positive effect on behavioural outcomes. Eggermont (2010) suggested that walking may be a key physical activity to demonstrate positive effects on mood, concluding that sustained walking may benefit affective behaviour. Studies involving carers demonstrated overall reduction in stress levels. Alessi et al. (1999) also showed benefits of walking on sleep. Comparisons of people who are mainly sedentary with those who are active showed that the active group had significantly better rest – activity rhythm (Eggermont 2008).

Cerga-Pashoja et al. (2010) designed a randomized controlled trial involving people with dementia/suspected dementia living at home with a carer willing to be a co-participant to evaluate the effectiveness of exercise as a therapy for behavioural and psychological symptoms of dementia (BPSD). The hypothesis being that a programme of tailored incremental exercise improves the symptoms of BPSD. Thurne-Boyle et al. (2012) results indicate that exercise appears to be beneficial in reducing BPSD especially depressed mood, agitation and wandering, however stating that evidence on improving symptoms such as anxiety, apathy and repetitive behaviours is currently weak or lacking.

In 2008 Forbes et al. concluded that in the studies they reviewed there was insufficient evidence of the benefit of physical activity programmes



on cognitive function, behaviour, depression and mortality in older people with dementia, stating that the lack of evidence may be due to methodological issues in the published studies. More recent studies show mixed results concerning the potential effects of physical exercise on cognitive function of people with dementia. However, Erickson (2011) concluded that physical activity e.g. aerobic exercise has emerged as a promising low cost treatment to improve neuro-cognitive function. Taking this into account future work would need to consider the following:

- + More studies are required that explore the potential neuroprotective role that aerobic exercise has in the management of dementia.
- + Scarmeas et al. (2011) states that exercise may affect not only risk for Alzheimer's Disease but also subsequent disease duration. On this basis there needs to be further exploration on the direct impact of physical exercise on cognition especially in relation to the potential benefits this may have on improving quality of life, physical health, affective symptoms and possibly influencing the rate of decline, the impact of physical activity on primary prevention is also important.
- + Exercise studies in dementia also need to consider the community-based nature of care and that exercise is intrinsically link to lifestyle.



## Innovate Dementia theme: Nutrition

Dementia, by its nature, does not lend itself to a clear and sequential pathway; people are affected in very different ways, this also applies to the issue of nutrition within a dementia context (NCCMH 2007; Kitwood 1997; Cantley 2001; DOH 2009). For many people with dementia, the changes that are experienced as dementia progresses can have an impact on their nutritional experience. These changes can result in weight loss, under-nutrition, dehydration and even weight gain. A study carried out by Volicer et al. (1988), illustrates that eating difficulties occurring in people experiencing Alzheimer type dementia were found to be experienced by the majority of those living in institutionalised care.

The importance of nutrition is emerging in dementia, nutritional advice and recommendations have started to be articulated in public information to help prevent or minimise the risk of dementia (DOH, 2009; Segal & Kemp 2012). Key to this recognition is the assessment of nutritional needs, allowing for a person's identity, cultural needs, likes and dislikes, is essential in the care of people with dementia (DOH 2001b). Green and Watson (2006) carried out a literature review of nutritional assessment screening tools in older adults. They identified 21 nutritional tools for use with older adults, covering a wide range of risks for malnutrition. Although these tools were used in clinical practice, many did not seem to have been tested for validity and reliability. They concede that nutritional screening tools can be useful to create a nutritional care plan, but they may not demonstrate sensitivity. Therefore, caution in choosing a tool was needed.

In terms of determining the correct nutritional elements and levels for people with dementia even though this work is in its early stages, there are a number of promising studies; Segal and Kemp 2012; Lim et al., 2006; Sydenham et al., 2012; Malouf et al., 2008; De Jager et al., 2012; Llwellyn et al.,

2009; Morris et al., 2002; Scheltens et al., 2012. The importance of this work is further highlighted when considering that in the United Kingdom, intakes of recommended levels of energy and macronutrients were not favourable in older people, particularly females. This was also found in relation to females consumption of protein and carbohydrate (apart from females in Ireland who met the recommended range of 50 – 75%E - WHO 2007).

For both sexes, total carbohydrate energy intake was also below the recommended level, as was the intake of fibre (Eurodiet 2000). In terms of the wider European picture, the European Nutrition and Health Report (2009) highlights that: "The share of protein in total energy intake per day was in the range of 13.6 and 19.0%E in male and 13.2 and 20.0%E in female elderly. Only Austrian, Danish, German, Greek, Hungarian and Polish male as well as Danish, German, Greek, Hungarian and Polish female elderly were within the recommended intake range (10–15%E) of the WHO [WHO, 2003]." Elmadfa, 2009: 144)

In terms of carbohydrate consumption: "*The share of total carbohydrates in total energy intake per day was between 39.1 and 51.0%E in male and between 39.1 and 52.6%E in female elderly. The recommended intake level of 50–75%E of the WHO [WHO, 2007] was only met by elderly from Norway and Portugal and by female elderly from Finland and Ireland. Whereas the proportion of total carbohydrates in total energy intake was lower than the recommendation, the share of sucrose in total energy intake was above the recommended level in both elderly males and females from Poland, Spain and the United Kingdom. In general, the intake of dietary fibers was below the recommended level (>25 g/day) of Eurodiet [Eurodiet, 2000]. Only Portuguese and German male elderly met the recommendation.*" ( Elmadfa, 2009: 144-145).

It was also noted that: "*The share of fat in total energy intake was above the recommendation of*

*the WHO [WHO, 2003] in almost every country.” (Elmadfa, 2009: 145).*

Elmadfa (2009) also reported that in 2007, only 27% of men and 31% of women across Europe ate more than five portions of fruit or vegetables a day. Further to this, a report by Segal and Kemp (2012) highlights that key nutrients which include a selection of brightly coloured fruit, leafy vegetables, fish and nuts packed with omega-3 fatty acids are essential for the brain to work effectively and can improve focus and help reduce the risk of Alzheimer’s disease (Segal & Kemp 2012). A systematic review was carried out by Lim et al. (2006) regarding the role of omega 3 fatty acid in the prevention of dementia (in people over 60 years old and without pre-onset of dementia at the start of the study). The review found that there is an increasing body of evidence to imply that Omega 3 PUFA could give protection against dementia. However, they suggest that until there is analysed data available from randomized controlled trials, there is no firm evidence to support the use of Omega 3 PUFA in the dietary or supplementary form in the prevention of cognitive impairment or dementia. A further review in 2012 by Sydenham, Dangour and Lim found that a dearth of direct evidence on the effect of omega – 3 PUFA on dementia, though it was noted that ‘none of the studies examined the effect of omega-3 PUFA on the incidents of dementia’ (pp.2). The study did recommend that: *“Further studies of longer duration are required. Longer-term studies may identify greater change in cognitive function in study participants which may enhance the ability to detect the possible effects of omega-3 PUFA supplementation in preventing cognitive decline in older people.”* (Sydenham et al. 2012: 2).

In relation to vitamins, a systematic review by Malouf et al. (2008) examined folic acid supplementation, with or without vitamin B12 for the prevention, progression delay and treatment of cognitive impairment. They found no consistent evidence

that folic acid, with or without vitamin B12 has a beneficial effect on cognitive function of either cognitively healthy or cognitively impaired older people. In comparison, a study by Bryan, Calvaresi and Hughes (2002) did find that short-term folate, vitamin B12, or vitamin B6 supplements slightly impacted on memory performance in healthy women of all age groups.

De Jager et al. (2012) carried out a randomized controlled trial to ascertain cognitive and clinical outcomes of homocysteine-lowering B-vitamin treatment in mild cognitive impairment (MCI).

*“Low levels of B vitamins are associated with cognitive impairment (Selhub et al., 2000; Caddon 2006; Smith, 2008). The biological pathways involved are probably related to formation of the amino acid homocysteine. If B-vitamin levels are lower than normal, total homocysteine (tHcy) levels in plasma increase. Plasma tHcy levels are known to increase with age (Refsum et al., 2004), and community-dwelling older people with higher-than-average levels of tHcy perform less well on cognitive tests than those with lower levels*

*(Smith, 2008).”* (De Jager et al., 2012: 593)

The study concluded that B- vitamin treatment over a period of two years slows the decline of cognitive test performance in MCI, with apparent improvement in clinical status, mainly in people with a high baseline level of total homocysteine (De Jager et al., 2012).

Generally vitamins have been cited in a number of studies (Llwelllyn et al. 2009; De Jager et al., 2012; Morris et al., 2002), concerning nutrition and older people. However, although there has been much conjecture concerning vitamins and dementia care per se, there seems to be a dearth of evidence of the conclusive benefit of them. Llwelllyn et al. (2009) notes that Vitamin D may play a part in preventing cognitive impairment but state that previous findings have been inconclusive. Morris et al. (2002)

studied whether intake of antioxidant nutrients, including vitamin E, vitamin C and carotene are linked to reduced cognitive decline with age and conclude that vitamin E is linked with less cognitive decline with age.

Another key area to consider relates to the research on food positioning. This includes the components of macronutrients in meals and their effect on cognition. Macronutrients are described as: *“an essential nutrient that has a large minimal daily requirement, including proteins, fats, carbohydrates and water. The term sometimes specifically includes, and sometimes specifically excludes, minerals required in amounts greater than 100mg daily: calcium, chloride, magnesium, potassium, phosphorous, sodium and sulphur.”* (Miller-Keane Dictionary and Encyclopaedia of Medicine, Nursing and Allied Health, 2003) [http://medical-dictionary.thefreedictionary.com/macronutrient.](http://medical-dictionary.thefreedictionary.com/macronutrient))

Research into meal positioning, tend's to have concentrated on healthy young people, particularly males, Orr, Shadid, Harnish and Elsenbruch (1997), Fischer, Colombani, Langhans and Wenk (2001), Akitsuki et al (2011). Fischer et al. (2001), in their study of cognitive performance and its relationship with postprandial metabolic changes after ingestion of different macronutrients in the morning (subjects were fifteen healthy young males) found that this relationship is inconclusive. They found that there is little understanding of how the many postprandial metabolic changes affect both complex and simple cognitive functions. Also, good and stable cognitive performance is related to a balanced glucose metabolism and metabolic activation state. The fat meal gave the best score of a focused attention test. There was more accuracy in short term memory after a carbohydrate, rather than a protein meal, but the opposite was the case for central efficiency and peripheral attention.

A study by Akitsuki et al. (2011) set out to ascertain whether nutritional quality of breakfast affects

cognitive function on six healthy right handed young males. The study indicates that 'significantly higher brain activation was observed in the medial aspect of the prefrontal cortex when the subject had a nutritionally balanced breakfast while the subjects were conducting N-back tests.' (p.192).

Green and Watson (2006) note that the incidence of malnutrition amongst older people is high. On this basis another promising area of research is the area of food supplementation. Very recently, Scheltens et al., (2012) carried out a multi country; multi centre randomized controlled trial on the efficacy of Souvenaid, a medical food designed for special purposes, under medical supervision, for use in early Alzheimer's disease. The study indicates that Souvenaid has a beneficial affect on cognitive function in mild AD, but concede that further investigation is needed. It also showed a positive safety profile and that Souvenaid was well tolerated (Scheltens et al., 2012).

In a systematic literature review of interventions to promote oral nutritional intake in older people with dementia Green and Watson (2006), assert that difficulty with feeding is common, particularly in the later stages. They concluded that further research is required into nursing interventions to assist older people with dementia to feed. Swallowing difficulties in people in the later stages can occur. Volicer et al. (1989) recognised in a study of people with Alzheimer type dementia almost a quarter of a century ago that 'eating difficulties can be managed without resorting to tube feeding' (p 188).

Percutaneous endoscopic gastronomy (PEG) feeding tubes are increasingly utilised for enteral nutrition on a long term basis when patients are unable to maintain adequate nutrition orally (Patient.co.uk 2012). PEG feeding is most commonly used in neurological disorders. However, its use in dementia care poses legal and ethical issues, particularly around mental capacity (Sampson et al., 2009); DOH, 2005, DOH, 2009). Chernoff (2006)



asserts that the benefit is minimal from nutritional support that is aggressive, with improvements being immeasurable in terms of life expectancy, weight, or reduction in complications such as pressure sores and aspiration. In a systematic review of the literature around enteric tube feeding, there was a lack of evidence to suggest the benefit of enteral tube feeding in people with dementia (Green and Watson 2008).

In conclusion, nutrition has a part in the ageing process and in relation to the management of dementia, though it is acknowledged that there is a pressing need for more high quality research which does not just focus cognitive impairment, which may or may not include dementia (González-Gros et al. 2001). As mentioned previously there is growing evidence that nutrition may play a part in improving cognitive impairment which is highlighted by a number of promising studies; Segal & Kemp 2012; Lim et al., 2006; Sydenham et al., 2012; Malouf et al., 2008; De Jager et al., 2012; Llwellyn et al., 2009; Morris et al., 2002; Scheltens et al., 2012; however, in terms of further research the following would need to be considered:

- + More controlled trials are required. These trials need to consider; the interventions needed to assist people with dementia to feed, the nutritional status at each stage of the condition, and also to ascertain which dietary supplements are most effective in the prevention of dementia and cognitive impairment.
- + A key area to improve would be to have a multi-professional, systemic approach, which incorporates nutritional needs into assessment more effectively. This would range from the use of assessment tools being developed and researched, and to ascertain which existing reliable and validated assessments are the most effective.

- + Studies often cite cognitive impairment and nutrition. However, it is important to clarify that cognitive impairment may not be due to dementia. Therefore, there needs to be more dementia specific studies especially studies that consider the community-based nature of care delivery.





## Innovate Dementia theme: Living Environment

One of the first authors to recognise the role of the environment in caregiving situations is Powel Lawton. His ecological model of aging focuses on aging in place as a person-environment phenomenon (Lawton, 1990). Human functioning can be seen as a result of the person's biological, psychological, and social resources, environmental characteristics, and the balance between continually moving and changing individuals and their continually moving and changing environments. Several authors built on these ecological theories and specifically investigated the role of the environment for persons with dementia.

Zeisel et al. (2003) demonstrated that there is an association between behaviour and particular environmental design features and described the potential that the environment has for contributing to improvements in the symptoms of dementia by being comforting, safe and understandable. Campion (1999) made the case for using the environment as an intervention in itself. Lawton (2001) acknowledged the vital nature of designing environments to meet the needs of people with dementia but described the challenge this presents in terms of robust research design to measure efficacy and impact on quality of life for people with dementia.

Early studies focused on single elements of design to overcome particular problems. As knowledge increased with regard to the complexity and difference of each person, so developed a more holistic approach to creating environments that go beyond meeting physical needs to environments that attempt to increase feelings of safety, security and comfort and acknowledge psychological needs (Calkins 2001). The systemic nature of settings was described by Calkins (2001) in the Integrated model of Place describing the connected nature of many elements which contribute to environments,

indeed, the physical environment can help people with dementia to achieve their potential, avoid increased disability, enrich and provide quality to lives (Davis et al. 2009) and can contribute to doing exactly the opposite.

A move of residence is often unhelpful for people with dementia as it increases the problems associated with memory loss. It is more effective to have a person's current home adapted than move to alternative accommodation as this provides a host of new challenges. Unfortunately models of care which have developed have meant that people are supported to live at home by informal carers, formal carers, community mental health services and technology but frequently a point is reached when people have moved into residential care. This is costly and not where most people want to be. Many levels of supported living exist within different areas and countries but with no general consensus or standardised approach. The different models will be briefly considered below.

### The Psychosocial environment

It would be an incomplete picture in describing environments and models of living if the psychosocial aspect of this was ignored. Although the physical environment is important perhaps more so is the psychosocial environment, particularly in residential settings for people with dementia. It can preserve personhood, reduce the need for anti psychotic medication and improve quality of life (Werezak and Morgan 2003).

Zimmerman et al. (2005) conclude that traditional organisational structure does not lend itself to a person centred approach yet we know this is recognised as best practice for supporting people with dementia. Person centred practice recognises the underlying needs of the person, the need for maintenance of self (Sabat and Harre 1992, Cheston and Bender 2000) which is often threatened by dementia.





Frequently environments are designed to keep people safe and provide some degree of control without addressing the underlying needs of the person. However, environments can never make up for poor quality care and support. Environments have the potential to improve quality of life and enrich the lives of people with dementia. This is within the context of person centred practice, staff training and organisational commitment.

### **Living at home**

Figures from the Alzheimer's Society for the UK (2012) indicate that two thirds of people with dementia live at home, one third live alone. There are 670,000 carers of people with dementia in the UK and family carers of people with dementia save the UK over £8 billion a year. The future provision of support is vital to prevent or delay admission to residential settings and provide the opportunities for people who wish to remain at home to do so.

Supporting people to live at home takes various forms. Since the launch of the National Dementia Strategy (DOH 2009) in the UK, the drive has been to increase early intervention services to prepare people for living with dementia, however in Belgium professional involvement comes later. The start of professional input in the UK usually takes the form of post diagnostic support (Lecourtierre et al. 2008), education and provision of information for people with dementia and carers. Evidence suggests equipping people in this way following diagnosis prevents crises and care home admission. Carer support and education programmes are vital alongside practical advice, problem solving and compensatory strategies at home. These are often provided in the UK by Occupational Therapists within memory services and Community Mental Health Teams. Financial advice and support is vital, as are the availability of personalised budgets for people to purchase more person centred support, available activities and day services and respite services. However the current economic climate

threatens the availability of such services. These services are often co-ordinated within Memory Services (Banerjee et al. 2007), which can be in a clinic or Community Mental Health Team setting, providing a coordinating role. The voluntary sector provides many services to support people living at home.

Lawton and Nahemow's (1973) competence environment press model describes how physical environment and disability are linked with environmental press referring to the demand that the environment makes on an individual while competence refers to the ability of an individual to respond adaptively to such demands. A person's functional performance is the result of the interactions between competence and environmental demand (person – environment fit) (Chappel and Cooke 2012). It can be seen that adapting and simplifying current environments in a systematic way can be vital in enabling independence and ability to cope at home.

A few rare studies describe the link between home environmental modifications and functional ability related outcomes (Wahl et al. 2009). Two such studies considering structured support consider the value of Occupational Therapy in this area. Gitlin et al. (2000) looked at providing Occupational Therapy at home for education, physical and environmental modifications. Caregivers reported fewer declines in patients' instrumental activities of daily living, less decline in self care and fewer reported 'behaviour problems'. Spouses reported less upset and enhanced self efficacy in managing behaviour and functional dependency. Graff et al.'s (2006) single blind randomised controlled study of 10 sessions of occupational therapy for people with dementia and carers living at home aimed to educate and provide compensatory and coping strategies. This demonstrated improved daily functioning and reduced stress on caregivers despite compromised learning abilities in the people with dementia, with



effects still present at 12 weeks. Improvements in activities in daily living and sense of competence are associated with a decrease in need for assistance. In the long term more effective use of occupational therapy could reduce dependence on social and healthcare resources and delay care home admission. Considering the use of high and low-tech solutions such as improved lighting, adaptations such as bath aids, prompts to memory, telecare systems (Alzheimer's Society 2008) and environmental design and advice re layout (Dementia Services Development Centre, 2007) should not be forgotten, as they can also help to increase autonomy for people with dementia and mitigate risks.

A more robust and systematic application of the above may reduce crises and prevent unnecessary and expensive admission to care homes. Chappel and Cooke (2012) describe the lack of common psychometrically sound home assessment tools as an area of concern. With many studies using service developed tools, thus making comparison difficult.

In northern European countries, they have successfully created models of conventional housing that are layered with supportive services that enable people to stay at home (Regnier and Denton 2009). Some places combine this with a life skills approach that encourages maximum involvement and independence in daily living activities. For example the 'Humanitas' apartments for life programme (Netherlands) which involves creating a conventional housing project open to a range of older people with a flexible design strategy and a philosophy that is designed to enable people to 'age in place'. The unit adapts to changes in ability and services ramp up as required although it is acknowledged that supporting people with cognitive problems and distress within this model is not without difficulties. (Regnier and Denton 2009).

#### Assistive technologies

Assistive technologies can support independence and enable people with dementia to live in situations or take part in activities, that might otherwise be deemed to be risky (Manthorpe 2010), offering great potential particularly for people who are living alone. Low and high tech solutions offer potential to promote independence and safety at home. Telecare systems utilise IT to promote and enable independent care in the community and home settings( e.g. Liverpool pilot, Reeves 2005) Telecare refers to devices that continuously, automatically and remotely monitor real-time emergencies and lifestyle changes over time. Sensors around the home can be linked via a telephone line to a nominated person or call centre. The system monitors a person's activities and, if a problem occurs, triggers an alert to a relative, keyholder or call centre (Alzheimer's Society, AT Dementia 2012). Evidence of the benefits of Assistive Technology for older people in general living in extra care include its contribution to people's sense of security (for example through being able to call for help in an emergency) and recognition by older people that it is a preventative measure (Alladice, 2005). Although a UK government aspiration anticipated the roll out to all people who required it by 2010, moving to mainstream service delivery has been far from straightforward due to organisational and cultural characteristics of local care institutions and the complexity of scheme objectives (Barlow 2005). Again a more systematic and robust application may offer potential increases in opportunities for continued independence.

#### SMART home technologies

SMART Homes provide support to remain at home autonomously and safely (Martin et al. 2008). The provision of smart homes is framed within the context of changing population profiles and involves social alarms, electronic assistive devices, alert platforms. Once installed, the systems are designed to closely monitor people's movements



and actions around the home. As well as providing voice-prompts (e.g. reminders to turn off a tap or cooker), they can also directly switch lights or appliances on and off in order to eliminate potential dangers. Therefore providing evidence that, if installed in domestic properties, systems like this could help people with dementia live safely and with more control over their lives, in particular this is useful where people live alone (BIME 2009).

The 'SAFE at Home project' in Northampton uses technology to enable people with dementia to live at home for longer. There was no evidence that the technology used in the project helped service users to regain lost independence, but there was considerable evidence that the use of technology helped maintain existing levels of independence, in comparison with a matched group of people with dementia who did not use technology, Safe at Home users tended to remain longer in their own homes.

Martin et al. (2008) found a lack of empirical evidence to support or refute the use of smart home technologies within health and social care. However, use of a SMART flat in Evans et al.'s (2007) study indicated a reduction in night 'wandering'.

### **Assisted living environments**

Assisted living (AL) has become an increasingly popular long-term care alternative for older adults over the last decade. Estimates suggest that 1 million older adults in America currently reside in AL facilities. However, philosophical and operational definitions of AL vary resulting in wide variations in environments, services offered, and policies about residents. In the USA AL has been described a wide variety of residential facilities for older people that provide personal care in activities of daily living and are able to respond to unscheduled needs for assistance, unless they are licensed as a nursing home (Zimmerman et al. 2005).

AL is a term that comes from the USA that encompasses residential care, sheltered housing,

domiciliary care, intermediate care housing, adult foster care (Zimmerman et al 2005). In the UK care homes are divided in three types (residential- lowest level of support, EMI residential- support for those with cognitive problems usually dementia and nursing- highest level of care for those with complex physical and mental health needs). For the purpose of this paper care home settings are included in care home section.

### Extra Care Housing.

In the UK Extra Care Housing (ECH) has developed as a model of housing that combines independent housing with flexible levels of care. There are a wide variety of types of extra care housing, along with many definitions and terminologies amongst which are 'housing with care', 'very sheltered housing', and 'assisted living'

There is evidence that people with dementia living in ECH generally have a good quality of life although studies show that some tenants with dementia can be at risk of loneliness, social isolation and discrimination (Dutton 2009).

Extra care can be an effective alternative to residential care, and can delay or prevent moves to nursing care, many people with dementia have been supported in extra care through to the end of their lives, however, this is not possible for everyone. There are few UK studies of extra care housing relating to tenants with dementia. The majority of the existing research evidence is from the USA and the studies researching cost effectiveness have been small scale as have the housing schemes so results are not persuasive.

### Care home/ group living environments

These take the form of residential homes, nursing homes, EMI nursing homes, special care units and also sometimes referred to as Assisted Living environments. In the past people with dementia were cared for in long term mental health



environments. In the 1990's the Domus philosophy (Lindesay 1991) was introduced providing the concept of home for life, developed in London in it provided small purpose built homes for people with dementia to replace traditional long stay hospital provision., the project aimed to address staff attitudes and aimed to correct the consequences of dementia by adapting the environment and making safety adaptations. In the last fifteen years the care home industry has become the provider for long term care for people with dementia. In Belgium it was found that the underlying principle of normalization is of central importance.

Traditionally care home environments have been established and designed around the principles of the medical model but this kind of design has become outmoded (Finnema et al. 2000). However, there remains a struggle within institutional context, trying to move the care of older people away from the medical model (which impedes individuality and choice) towards a social model of care. Shifting the emphasis away from the physical conditions to think about the person's experience can encourage cultural change, Davis et al. (2009) and Calkins (2009) describes the move from a focus on challenging behaviour to a more inclusive approach exploring emotional states and wellbeing as the most significant evolution in research over the past decade within long term care design. Care home environments are difficult places for people with dementia to be. Zuidema et al. (2010) reported that the clustering of neuropsychiatric symptoms in special care units is strong evidence for the contribution of the environment. However even the benefits of the best environments can be undermined if organisation structure and culture is not good (Calkins 2002).

The change in culture within dementia is influencing design. Chalfont and Rodiek (2005) discussed that it is time to move beyond the purpose of designing environments to aid control or diminish behavioural

difficulties and make steps towards understanding how environments actively encourage pleasurable and satisfying behaviour. People with dementia are challenged by large, unstructured space with a large, unpredictable number of people sharing the space (Alzheimer's Australia 2004). Experts recommend units from between 8 and 12 residents can retain domestic character (Morgan and Stewart 2004). A small scale (unit size) is necessary but not enough to attain a normalized living. In 1998 Van Audenhoveea limited group size from 16 to 6 persons.

The principles of dementia friendly environments are now widely recognised and essential for care home design. A study by Bicket et al. (2010) indicated that the physical environment in assisted living facilities likely affects neuropsychiatric symptoms and quality of life and increasing privacy and communication aids may also improve wellbeing.

It is difficult to define dementia friendly environments. This kind of environment would focus on the experience of the person and the organisational, social and physical environment which impacts on the person's experience. Dementia friendly environment principles should cross boundaries in terms of living arrangements as be applied wherever the person is living, such as:

+ Room function and design.

Each room needs to look like what its function is, the furnishings should help orientate the person to the room function. Residential character is associated with reduced social withdrawal, greater independence, improved sleep and more family visits (Minde et al. 1990). Day et al. (2000) stated that homelike furnishings, personalisation and non institutional character increases wellbeing and social interaction, reduces agitation, exit seeking behaviour (Cohen Mansfield and Werner 1998, McAllister and Silverman 1999, Sloane 1998). Calkins (2002) states that the building is more



than a house. It needs to be a home to connect with feelings of safety and security, being in control and having stability and unsurprisingly common areas with unique, non- institutional character are associated with reduced social withdrawal (Gotestam and Melin (1987). Rooms people are to go in should be bright, attractive and inviting.

#### + Lighting

Ageing processes means less light is perceived and there is slower adjustment from dark to light so older people require higher levels of light. Sloane et al. (1998) found that low level overall lighting was related to higher agitation levels There is also an increased sensitivity to glare (Brawley 1997) as light falls on shiny /sparkly floors, it can be perceived as wet or water so people will be fearful of stepping on it (Marshall 2012). Improved lighting is associated with improved sleep patterns and improved circadian rhythms (Day et al. 2000)

#### + Way finding and signage

Signage is vital. Environments need to be understandable, with easily recognisable landmarks to enable way finding and signs at decision making points. Individualising people's doorways is a helpful way to help them find their rooms. Positioning of signs is important, placing signs on doors not next to them and at eye level. Signs should be accompanied by pictures to maximise understanding.

One of the main issues highlighted is of people attempting to leave. In the past strategies such as using mirrors on doors, painting murals over doors, painting black lines in front of doors were used to deter people from trying to leave. These strategies exploited the cognitive deficits of the person. More recently more enlightened approaches aim to understand the cause of the behaviour which is often related to unmet needs for safety and security and once the underlying need is met the behaviour will change (Kitwood 1997). Day et al. 2000 reported that unlocking doors and enabling access to secure

outdoor space was associated with significant decrease in agitation levels.

Camouflaging exits is still used and Ziesel et al (2003) and Dickinson and McLain-Kark (1998) found exits that are not easily identifiable reduce elopement attempts. Camouflaging refers to exits on side walls rather than on the ends of corridors, smaller exit signs, unobtrusive doors and exit doors that look like non- exit doors. Painting doors that people do not need to use the same colour as the wall detracts attention away (University of Stirling 2012). The absence of visible door hardware that attracts attention, solid or opaque doors rather than glass ones as they attract less resident attention and doors which open into a safe location.

Parker et al. (2004) expressed a view that stringent health and safety requirements negatively affect the quality of life of residents. Security measures are strongly associated with self destructive behaviour.

#### + Flooring

Often perception can be affected in dementia, therefore depth, colour and space is perceived differently. Shiny/sparkly floors and deep colours tend to give people with dementia with perceptual problems the impression of water or a hole so they are fearful of stepping onto it. Sparkly floors or floors with gravel effect can cause people to stop and try to pick up the gravel as it is perceived as loose. Therefore flooring should be the same colour, avoid changes at thresholds as this can appear as a step and may cause people to stop at doorways (DSDC 2012).

#### + Colour and contrast

Colour is helpful in helping people orientate themselves and some studies use coloured doors to help guide residents. Obvious use of colour can help orientate people, increase security and reduce anxiety and distress. Use contrast with chairs and flooring as green chairs on a green carpet are



often difficult to see. Contrast needs to be used in toilets to help distinguish the toilet from the white background of tiles and flooring. The use of contrast is also helpful at mealtimes with crockery.

#### + Personalisation

Personalising the environment of people with dementia has long been recognised as vital in reducing anxiety and stress levels and affirming sense of self. The degree to which residents are encouraged to personalise their environment is often very limited, however environments ought to include treasured possessions, furnishings, choice of colour and pictures (Davis et al. 2009). Personalisation can provide comfort and feelings of safety and security, it can impact positively on levels of independence in activities of daily living (Reimer et al. 2004) and demonstrate important implications for quality of life (Phillips et al. 1997).

#### + Unit size

Also important is the size of the group living together, there is a move away from large scale residential units to smaller unit size, possibly 8 people to retain domestic and residential focus (Zeisel 2003). Larger unit sizes are associated with increased levels of agitation, anxiety, distress and cognitive decline (Day et al. 2000). People with dementia are challenged by large unstructured space (Alzheimer's Australia 2004) and small group living clusters are preferable, like the 'Green House model' (Regnier and Denton 2009).

#### + Levels of stimulation

Over and under stimulation are major problems in care home environments and can increase agitation, confusion and withdrawal (Day et al. 2000). The balance needs to be sought between over stimulation and sensory and occupational deprivation (Perrin and May 2000) as each is potentially harmful. Verbeek et al. (2008) highlight the need to use daily life activities which centre

around the home to increase engagement and quality of life

Environments should be visually stimulating and ambient sensory environments, considering the use of familiar smells, sights, sounds and recognising the importance of touch and tactile stimulation (Price and Grout 2009). Stressful areas can be corridors, lifts, nursing stations, bathrooms (McWerner and Marx 1990). Therapeutic garden access reduces elopement attempts and improves sleep (Stewart 1995). Opportunities to go outdoors are vital. There should be full access to an adjacent garden space with good design to provide sensory feedback for the residents, space to walk and sit, places to be away from other residents and activities being run in the garden.

There are many examples of innovative care facilities and approaches where environmental considerations are paramount (Green Homes USA, Hearthstone USA, Hogeweyck Netherlands). The design of the built environment alone and combined with organisational policies and procedures has direct and measurable impact on the physical and psychosocial functioning of residents with dementia which may translate into higher quality of life (Regnier and Denton 2009).

Waller (2010) reports that many hospitals were not designed with patients in mind. There is a huge national agenda to improve the care of people with dementia in general hospitals and much of this is aimed at environmental design as the potential of the environment to improve the experience of people with dementia in general hospitals is huge. To this end there are now a range of environmental audit tools available (DSDC, Kings Fund 2012)

Irrespective of where a person with dementia is living it is apparent the potential that the environment has for increasing independence, quality of life and reducing unnecessary distress and harm. In 2001 Marshall reviewed the international literature for



designing dementia facilities and more recently has developed dementia friendly design principles for hospital environments (Marshall 2012). Wherever the person is, the environment needs to:

- + Maximise understanding and orientation
- + Maximise independence and maintenance of function
- + Reduce anxiety and distress
- + Reinforce the person's self identity
- + Maximise feelings of safety, comfort and security

In conclusion Parker et al. (2004) recommend that there should be a balance between choice and control, physical support, normalness and authenticity, comfort, cognitive support and personalisation as these are all associated with increased quality of life. Personalising people with dementia's environments has long been recognised as vital in reducing anxiety and stress levels and affirming sense of self. The degree to which residents are encouraged to personalise their environment is often very limited. Privacy reduces aggression and agitation and improves sleep (Morgan and Stewart 2004).

A systematic approach to maximising the potential for independence at home is essential rather than the long term expectation of care home admission. Innovation, technology and assistive living are key to maximise opportunities for a person to live independently as possible for as long as possible, whilst also ensuring that environmental innovations and resources are affordable, sustainable in the context of the aging population. There is a need to consider the following:

- + A holistic approach to the environment should always be considered. Environments are more than physical spaces, maximising independence,

autonomy and wellbeing comes from ensuring a person's psychosocial as well as physical needs are met.

- + Design should be influenced by promoting independence and normalising living, rather than control. Flexible care environments are important to enable people living with dementia to 'age in place' and prevent unnecessary admissions to care homes or hospitals
- + Future environment models need to utilise the principles of dementia friendly environments design coupled with home care style methods (Calkins 2009). These principles should cross boundaries and be applied to wherever a person is living.



## **Innovate Dementia theme: Models of assistance for people living with dementia and their carers**

Living with dementia impacts upon individuals, families and society. The direct and indirect cost of supporting people in a co-ordinated and equitable manner spans social, health and economic boundaries. It is essential that as ageing societies we recognise the complex social, health and economic impacts that arise as a person's dementia journey progresses and respond proactively to the increasing prevalence of dementia and the unsustainable existing health and social care provision (World Health Organisation and Alzheimer's Disease International 2012).

Traditional models of care are outdated, citizenship and social inclusion models have slowly gained momentum leading to a move towards individualisation and personalisation of care. The changing culture of care should lead to more choice, accessibility and flexible support to enable people with dementia to live where they want to be through their experience of dementia. The aspiration held by most is to remain as independent as possible, for as long as possible, in the place you want to be – home (Gitlin 2000). At present however, there are different models of care and support within different cities, regions and countries without a general co-ordinated approach.

The design of services has progressed over the last ten years, increasing the opportunities to maximize change to a certain degree. However there tends to be an unwritten caveat that when a certain point is reached care home admission is unavoidable. This is a costly and often an unsatisfying experience for many, although not without exception. A 'risk averse' culture, a term which describes a culture where professionals and society as a whole seek to eliminate risk completely, often develops when supporting people with dementia due to limited choice and innovative solutions. Whilst being

risk averse may appear a worthwhile intention, the degree to which this is carried out can stifle and indeed compromise a person's autonomy and human rights. Being 'risk averse' has led to premature admission to care home for many people living with dementia as alternatives are few and options, tools and new approaches are limited. Reports of significant concerns across the whole dementia journey continue, including low diagnosis rates, poor access to services, prolonged hospital stays, too early admissions to nursing homes; poor care, isolation, neglect and despair, and inadequate information, advice and information for carers (DOH 2012a).

There has, however been many changes occurring in health and social care systems to improve the accessibility and affordability of support, increase choice and offer individually oriented innovative solutions. For example in all partner countries, the introduction of personalisation or self-directed support, where people with dementia can receive personal budgets via health or care insurance, to enable more choice and freedom for support options. Although choice and freedom are central to the personalisation agenda, some current barriers identified are low levels of awareness and understanding, choice of options available, strong bureaucracy and possible abuse (Manthorpe, 2009, AWBZ-kompas 2011, CIZ-indicatiewijzer 2013).

To help confront today's health and social care challenges it is important to develop sustainable, innovative and integrated networks of care to support people living with dementia. It is equally as important that current and future models of care are influenced by and reflect the needs and expectations of people with dementia and their carers in order to maintain sustainability.

Engaging service users and carers in the design and creation of products and services is relatively



new within health care. However the underlying principle of professionals working alongside people living with dementia in order to generate ideas, co-design services or co-create products is innovative and essential to meet the needs of people living with dementia (end user). It is important that today's health and social models across North West Europe value the expertise of people living with dementia and challenge the perception of service users as passive recipients of care (The King's Fund 2012, Ham et al. 2012).

Bringing businesses and creative technologists into the equation, with health and social care staff, academia and people living with dementia, to develop solutions to everyday dementia related challenges is also relatively new within health and social care (Open labs 2012). Innovations in health and social care need to move beyond traditional models of working to consider how new ideas and technology can be used to improve the lives of people living with dementia. Assisted living technologies and services can promote health and wellbeing, provide high quality health and care and enable people to live as independently as possible for as long as possible. Whilst also ensuring that health and social care systems are affordable and sustainable in the context of an aging population, with diverse needs (Delivering Assisted Lifestyles Living At Scale (DALLAS) 2012).

### **Raising awareness and timely diagnosis**

Dementia is now recognised as a public health concern. However despite increasing awareness and intelligence globally, there continues to be a lack of public understanding around dementia which contributes to fear, stigma, social exclusion and age discrimination, thus resulting in later diagnosis, social isolation and delay in seeking help (WHO 2012, DOH 2009, NICE/SCIE 2006, National Collaborating Centre for Mental Health 2007).

There is often a significant delay from when people first notice concerns, typically memory problems and when they seek professional advice. Hesitance to seek advice and support arises from lack of understanding of the symptoms of dementia, a perception that early symptoms of dementia are a normal part of the aging process, a belief that there is no point in seeking help and an basic fear in the over 55 years age group of dementia, more than that of any other condition (All-Party Parliamentary Group on Dementia 2012, Alzheimer's Research Trust 2008).

A public health approach, based upon national dementia awareness campaigns are now common in the media. It is hoped that reliable and high quality information, especially concerning the benefits of early diagnosis and living well with dementia, can overcome barriers to identification and encourage first contact with professionals. Transnationally, a number of dementia organisations have comprehensive campaigns and websites for use by professionals and the general public that urge people with memory problems to see their GP. These organisations also offer internet platforms accessible to professionals and the public, interaction forums, blogs and intergenerational programmes, such as 'Alzheimer&you' in Germany where pupils and youths are informed about and integrated in the support for people with dementia.

In 2012, the UK Prime Minister, David Cameron, issued a national challenge on dementia committing to boost dementia research, address the quality of dementia care, increase public understanding of dementia and make communities more dementia friendly. The very public challenge and launch of the 'Dementia friends' website in England aims to to give a million people a better understanding of dementia by 2015, to find about what it is like to live with dementia and then turn that understanding into action in their local community.

An important Dementia initiative in the



Netherlands over the last decade is the establishment of the 'AlzheimerCafé', developed by Psychogerontologist Dr. Bère Miesen in 1997. This is a monthly informal meeting for people living with dementia, relatives and other people who are interested. The Alzheimer cafe usually starts with an educational aspect related to a dementia specific topic. After which visitors can share ideas, information and individual experiences with each other. Accessibility is important to success, therefore Alzheimer The Netherlands (Alzheimer's Netherlands 2013) and regional partners have established more than 220 cafes in the Netherlands, mostly located within 15 km from a user service like a memory clinic.

In Germany many initiatives are started by the German Alzheimer Association (Deutsche Alzheimer 2013), who provides a full spectrum of information, as well as personal phone counselling, known as 'Alzheimer Telefon'. A personal union with the president of the German Alzheimer Association and the president of Alzheimer Europe, Ms. Heike von Lützu-Hohlbein contributes to an international progression and harmonization of offers and information across countries. Recently the Ministry of Health for Germany supported the implementation of regional service structure developments and pilots to help improve the lives of people living with dementia, through programmes such as 'Zukunftswerkstatt Demenz'. Further commitment is reflected by governmental close organisations like the 'Aktion Psychisch Kranke e.V.', an association that is chaired by the eve ruling party and from professional organisations such as the Germans Association of Geriatric Psychiatry 'Deutsche Gesellschaft für Gerontopsychiatrie' and the National Association of Geriatric Psychiatry 'Landesverband Gerontopsychiatrie NRW'.

### **Specialist assessment services / diagnosis and assessment:**

A diagnosis of dementia creates the opportunity for a person and their family to access treatment and support services, it allows both the person with dementia and their family a chance to plan for the future and gain knowledge and understanding of what is happening to them (NICE/SCIE, 2006; NICE 2007, DOH 2009; Moniz-Cook and Manthorpe, 2009). Research shows that early diagnosis and intervention is cost-effective and can improve the quality of life for people with dementia and their families. However, it is still not that uncommon for people with dementia to never receive a diagnosis (All-Party Parliamentary Group on Dementia 2012). Still a significant number of people either do not receive a specialist diagnosis at any time or receive a diagnosis so late; up to twenty months post first consultation (Bond et al. 2005) or in a time of crisis when it is then too difficult to prevent harm, such as break down of family caring structures or admission to care settings (Knapp et al. 2007).

The coordination of clinical and social based assessment and diagnosis of dementia varies across countries' national health care systems. In the UK a person is primarily seen by their GP, then older people's mental health services, supported by old age psychiatrists and older people's specialist clinicians. Whereas there are variations in other countries in North West Europe of how this happens. In the Netherlands the coordination of assessment and diagnosis is mainly undertaken by geriatricians, specialist old age psychiatrists and neurologist's from memory clinics within general hospitals, mental health services (mainly geriatricians and the focus is on BPSD) and more recently by nursing home physicians.

In Germany assessment and diagnosis of dementia is under taken by General practitioners as well as



by specialists. There is also a network of memory ambulances 'Gedächtnissprechstunde' that provide guideline oriented diagnosis and treatment, however, early identification and diagnosis needs further improvements. Models and service structures have been developed to address this, for example in Northrhine-Westfalia (NRW) Gerontopsychiatrische Zentren (Centres of Geriatric Psychiatry), supported by government are multi-professional services which facilities access to specialist knowledge, helpful especially the beginning of dementia. A country wide organisation was established by the government to improve dementia awareness across all regions of the country and a further initiative of the Ministry of Health aimed at identifying people with that dementia admitted to acute general hospitals.

A consultation exercise with dementia experts drawn from eight EU states in 2005 found that there were widespread reservations among primary care doctors to make a diagnosis of dementia (Vernooj-Drassen et al. 2005). Although systematic population screening for dementia is not suggested, it has been recommended that Primary care workers and other health and social care professionals in contact with people with an established risk of dementia, should routinely ask questions to identify symptoms of dementia. However this is at times hindered by a lack of professional knowledge about dementia (DOH 2009) and also the lack of clear information, and psychological support that can be offered to both people living with dementia and their families (Audit Commission, 2000).

The All-Party Parliamentary Group on Dementia (2012) reported that under-diagnosis and/or misdiagnosis also came from professional's difficulty due to non-standardisation of assessment tools. Problems included that cognitive tests were inaccurate assessing decline in functioning, particularly in pre-morbid high functioning individuals, some tools used only focused on cognition and missed

other symptoms of dementia and copyright issues (All-Party Parliamentary Group on Dementia 2012). In addition Toot et al. (2012) undertook a review of geriatric psychiatric professional training structures in Europe, such as the content of specialist training, published with support of the European Association of Geriatric Psychiatry (Gustafson et al. 2003). In addition a consensus statement was also published by international professional organisations based on the ethical basis of working with older adults skills based objectives for specialist training in old age psychiatry (Katona et al. 2009).

Memory services exist in all Innovate Dementia regions for people with mild to moderate dementia. The aim of a memory service is to empower people with dementia and their carers to make informed choices and decisions about their quality of life and their future, to provide early diagnosis and education and to promote interventions for people with mild to moderate dementia (DOH 2011).

In the UK, the National Memory Services Accreditation Programme (MSNAP), accredited by - Royal College of Psychiatrists was established to assure and improve the quality of memory services for people with memory problems/dementia and their carers, recognising good practice and high quality care benchmark equity. An acknowledged area of 'best practice' in the UK is the Croydon Memory Service Model (CMSM) due to its recognition of the need for a co-ordinated and equitable response to early identification and intervention in dementia. The CMSM reflected a multi-agency approach with joint ownership by health services, social services and the voluntary sector. Other service providers in the UK have modelled themselves on this model since recognition.

### **Living well with dementia**

The increased number of people living with dementia places greater pressure on both the current formal and informal care and support provision available. Dementia not only has a devastating impact on



those with the disorder, but also has profound, more often negative effects on family members who provide the majority of care. Family carers are often old and frail themselves and have high levels of carer burden, depression and physical illness, and decreased quality of life DOH (2009)

Currently the majority of care for people with dementia is provided by unpaid carers and with 50-80% of care taking place in a person's home the burden on carers will increase as the person with dementia's needs increase (Alzheimer's Europe 2006). Informal carers, such as family members play an essential part in caring, however with people having fewer children (Eurostat 2009), changes in employment patterns of adults, in particular women (ONS 2012a) both men and women working beyond the age of 65 years (ONS 2012b) due to raising the age of state pension age (DWP2011), family members and carers are needing to stay in employment for longer, therefore less able to provide lengthy informal care.

Living well with Dementia is a goal that is mirrored in all partner's plans and future strategies. Living well with dementia means enabling people with dementia and their carers the experience of good-quality care, from diagnosis to the end of life, in the community, in hospitals and in care homes environments (DOH 2009). Although there are examples of disappointing or unsatisfactory quality care, many other get it right or are moving in the right direction. Across Europe there are excellent and innovative practices and developments that if shared, can accelerate and enhance NW Europe's capacity to innovate, facilitate new developments and learn from innovate knowledge based approaches and best practice.

### **+ From diagnosis to the end of life**

Network of care from diagnosis to end of life

must meet the needs of all people living with dementia, at whatever stage they are on their journey, encompass health, social and economic dimensions. However, developing a dementia network is a complex process as each individual's dementia journey is different. As well as dementia being an umbrella term for a number of different conditions, each individual will present with different difficulties, physiological changes, psychological and behavioural reactions and each family and community will respond differently, requiring varying levels of support at different time (Irving and McGarrigle 2012).

Placing people with dementia at the centre of the care network and tailoring support to their individual needs is essential. The involvement of people with dementia and carers in service development has led to innovative developments, such as the EDUCATE Project (Early Dementia Users' Co-operative Aiming To Educate). Here people with dementia take the role of educator and attend training events to inform others about the experience of dementia, with the aim to positively influence policies and promotes improved services (North West Joint Improvement Partnership 2010). The DEEP project (Dementia Engagement & Empowerment programme) is an example of large scale engagement project to empower and engage people living with dementia and collate opinion with regard to developing services and changing culture to meet need. (Williamson 2012).

### **+ Community, in hospitals and in care homes environments**

The living environment should be responsive to the personal needs and preferences of people living with dementia, wherever they reside, either temporarily or permanently. Many examples of innovations and technologies to maintain independence is a person's living environment have been discussed in



the previous chapter, living environments.

Compensatory strategies and the use of assistive technology, such as telecare can maintain people's independence at home, enabling people with dementia to remain at home alone safely and for longer period of time. In addition utilising Assistive technologies, a term used to describe a range of personal devices designed to enhance, physical, sensory, and cognitive abilities, therefore enabling people to function more independently (Kerr et 2010).

The rising prevalence of dementia will have an impact on acute hospitals services. The relationship between dementia and co-morbidity with general physical health conditions is high; resulting in approximately one in four inpatients in acute hospitals have dementia (Lakey 2009). However, many hospitals struggle to provide the high-quality care that is needed for people living with dementia within an acute hospital setting. Acute hospitals are equipped to provide specialised physical care, unfortunately, this is often without a satisfactory response to a person's mental health condition. Due to high co-morbidity with physical health conditions, typically people with dementia often stay in hospital longer, resulting in extra cost pressures and extra resources for mental health liaison, intermediate care and palliative care services (National Audit Office 2010).

In the UK, the Commissioning for Quality and Innovation (CQUIN) enforced that part of a hospital income will be dependent on meeting a target for every person over the age of 75 admitted to hospital being asked questions about their memory (DOH 2011). To support high-quality dementia care, key priorities are that staff are skilled and have time to care for people with dementia; staff work in partnership with carers; assessment and earlier identification and diagnosis is prioritised, care and care planning is individualised and the hospital environment is

dementia friendly. (RCN 2013). In addition, the provision of mental health liaison services for older adults within acute hospital settings is accepted as good practice (DOH 2009, NICE 2007) as this provide an additional layer of support and advise, dementia care planning guidance and education and training. (NICE 2007).

The role of a 'care navigator' to support a person living with dementia, regarding of setting and throughout their journey has been developed in several areas. The principle of this role is from diagnosis onwards, acting as a point of regular contact, signposting and guiding to services and care providers, never discharging the person. Care navigators can act as a resource to enable the person to access support as needs change, often preventing crises admissions through accessing timely support and 'navigating' a complex system of care (DOH 2009). As people progress in their dementia journey, the network of care can become more complex, as more care is required, and often palliative care.

In conclusion it is essential to recognise the complex social, health and economic impacts that arise as a person's dementia journey progresses and respond proactively to the increasing prevalence of dementia and the unsustainable existing health and social care provision. There is a need to consider the following:

- + A changing culture of care should lead to more choice, accessibility and flexible support to enable people with dementia to live where they want to be through their experience of dementia. The aspiration held by most is to remain as independent as possible, for as long as possible, in the place you want to be – home
- + It is essential that current and future models of care are influenced by and reflect the needs and expectations of people with dementia and their carers in order to maintain sustainability. People living with dementia should be central to





generating ideas, co-designing services or co-creating products.

- + Assisted living technologies and services can promote health and wellbeing, provide high quality health and care and enable people to live as independently as possible for as long as possible along their dementia journey
- + A network of care from diagnosis to end of life must meet the needs of all people living with dementia, at whatever stage they are on their journey, wherever the person resides, either temporarily or permanently.



### Section 3: Discussion

Dementia is one of the greatest challenges facing our ageing society. Whilst there has been major progress in recent years in securing public and political commitment to dementia, we now need to ensure that this commitment is turned into concerted action (National dementia declaration for England)

Globally there remains a degree of uncertainty as to future statistical figures for dementia (more or fewer years spent in ill health). Medical advances could delay or limit the impact of ageing and dementia, equally increasing risk factors such as obesity may increase the number of years spent in ill health. This uncertainty also makes it difficult to determine whether increased life expectancy will delay or increase the costs of ageing (Ham et al. 2012). However what is clear is that if the status quo is maintained in terms of service delivery and provision, in the future with increased life expectancy it will be economically unsustainable, increasing the urgency to find a solutions to today's challenges.

To enable fundamental changes to be made in the care quality and outcomes of people living with dementia, innovations in health and social care need to move beyond traditional models of working to ensure they are 'fit for the future'. Models and delivery of care need to focus on tomorrow's challenges, rather than those of yesterday, be sustainable and affordable and be user led (Ham et al. 2012). Increasingly, individuals rely on technology in most aspects of life, such as TV, computers, satellite navigation, and mobile phones. This technology has the potential to guide people, keep people safe and enable people to communicate with each other. The same access to and benefit from technology should to be available to, and continue to be used by people living with dementia in order to help maintain independence and quality of life (Kerr et al 2010).

The aims of the Innovate Dementia baseline report were to establish today's approaches in dementia care across partner regions and to provide a knowledge platform and benchmark to define the project's implementation plan and actions, specifically intelligent lighting, nutrition and exercise, Living environment s and models of assistance for people living with dementia. In Summary of the findings:

**Lighting:** There is promising evidence that light can be used as a therapy and as way of improving the environment for individuals with dementia, however there is need to consider the following;

- + More controlled trials, certainly within the area of symptom management. Trials must consider such technical factors as the intensity, duration, spectral content, and method of exposure of the light therapy
- + Light therapy research has to be care-packaged focused, for example future research would not just consider the rest-wake cycle in isolation it would need to consider rest-wake activity cycle in conjunction with diet and exercise, and it would also have to consider the community-based nature of care delivery
- + Future research would have to consider lighting as a way of managing the environment; and it would need to consider any future training requirements in the use of lighting and light therapy including the development of specific assessment tools (Lawton, 1997).

**Exercise and nutrition:** there is mounting evidence to support primary prevention in all adults, particularly those in their 40s and 50s, however more research is required. There is a need to explore and promote the impact of nutrition and exercise to enable people to live well with dementia There is a need to consider the following:

- + More studies are required that explore the

potential neuroprotective role that aerobic exercise has in the management of dementia.

- + Exercise may affect not only risk for Alzheimer's Disease but also subsequent disease duration. On this basis there needs to be further exploration on the direct impact of physical exercise on cognition especially in relation to the potential benefits this may have on improving quality of life, physical health, affective symptoms and possibly influencing the rate of decline, the impact of physical activity on primary prevention is also important.
- + Exercise studies in dementia also need to consider the community-based nature of care and that exercise is intrinsically link to lifestyle.
- + Further studies need to consider the interventions needed to assist people with dementia to feed, the nutritional status at each stage of the condition, and also to ascertain which dietary supplements are most effective in the prevention of dementia and cognitive impairment.
- + A key area to improve would be to have a multi-professional, systemic approach, which incorporates nutritional needs into assessment more effectively. This would range from the use of assessment tools being developed and researched, and to ascertain which existing reliable and validated assessments are the most effective.
- + Studies often cite cognitive impairment and nutrition. However, it is important to clarify that cognitive impairment may not be due to dementia. Therefore, there needs to more be dementia specific studies especially studies that consider the community-based nature of care delivery.

**Living Environments:** a systematic approach to maximising the potential for independence at

home is essential rather than the long term expectation of care home admission. Innovation, technology and assistive living are key to maximise opportunities for a person to live independently as possible for as long as possible, whilst also ensuring that environmental innovations and resources are affordable, sustainable in the context of the aging population. There is a need to consider the following:

- + A holistic approach to the environment should always be considered. Environments are more than physical spaces, maximising independence, autonomy and wellbeing comes from ensuring a person's psychosocial as well as physical needs are met.
- + Design should be influenced by promoting independence and normalising living, rather than control. Flexible care environments are important to enable people living with dementia to 'age in place' and prevent unnecessary admissions to care homes or hospitals
- + Future environment models need to utilise the principles of dementia friendly environments design coupled with home care style methods. These principles should cross boundaries and be applied to wherever a person is living.

**Models of assistance:** It is essential to recognise the complex social, health and economic impacts that arise as a person's dementia journey progresses and respond proactively to the increasing prevalence of dementia and the unsustainable existing health and social care provision. There is a need to consider the following:

- + A changing culture of care should lead to more choice, accessibility and flexible support to enable people with dementia to live where they want to be through their experience of dementia. The aspiration held by most is to remain as independent as possible, for as long as possible, in the place you want to be – home



- + It is essential that current and future models of care are influenced by and reflect the needs and expectations of people with dementia and their carers in order to maintain sustainability. People living with dementia should be central to generating ideas, co-designing services or co-creating products.
- + Assisted living technologies and services can promote health and wellbeing, provide high quality health and care and enable people to live as independently as possible for as long as possible along their dementia journey
- + A network of care from diagnosis to end of life must meet the needs of all people living with dementia, at whatever stage they are on their journey, wherever the person resides, either temporarily or permanently.

The next phase of the Innovate Dementia project is to determine which elements of innovation are crucial to implement in the Living Lab real life testing phase. Living Labs are established in the Netherlands, Germany and United Kingdom. Each Lab will include all four themes of the project: lighting, environment, exercise and nutrition and models of assistance, but will also be specific experts and coaches in one of them. Transnational sharing of results will ensure that each partner's regional Lab will benefit from the experiences gained in the other Labs. Sharing will happen through benchmark visits, staff exchange, trainings, joint working, etc., bringing together all relevant stakeholders from the public, medical and business sector.

One final transnational collaborative report, based on the living lab experience and pilot results will then link to the final recommendations in a business support plan, focusing on 'small to medium enterprises' (SMEs) and an endorsement plan for policy action at regional, national and EU level, linking to health policies at EU level.



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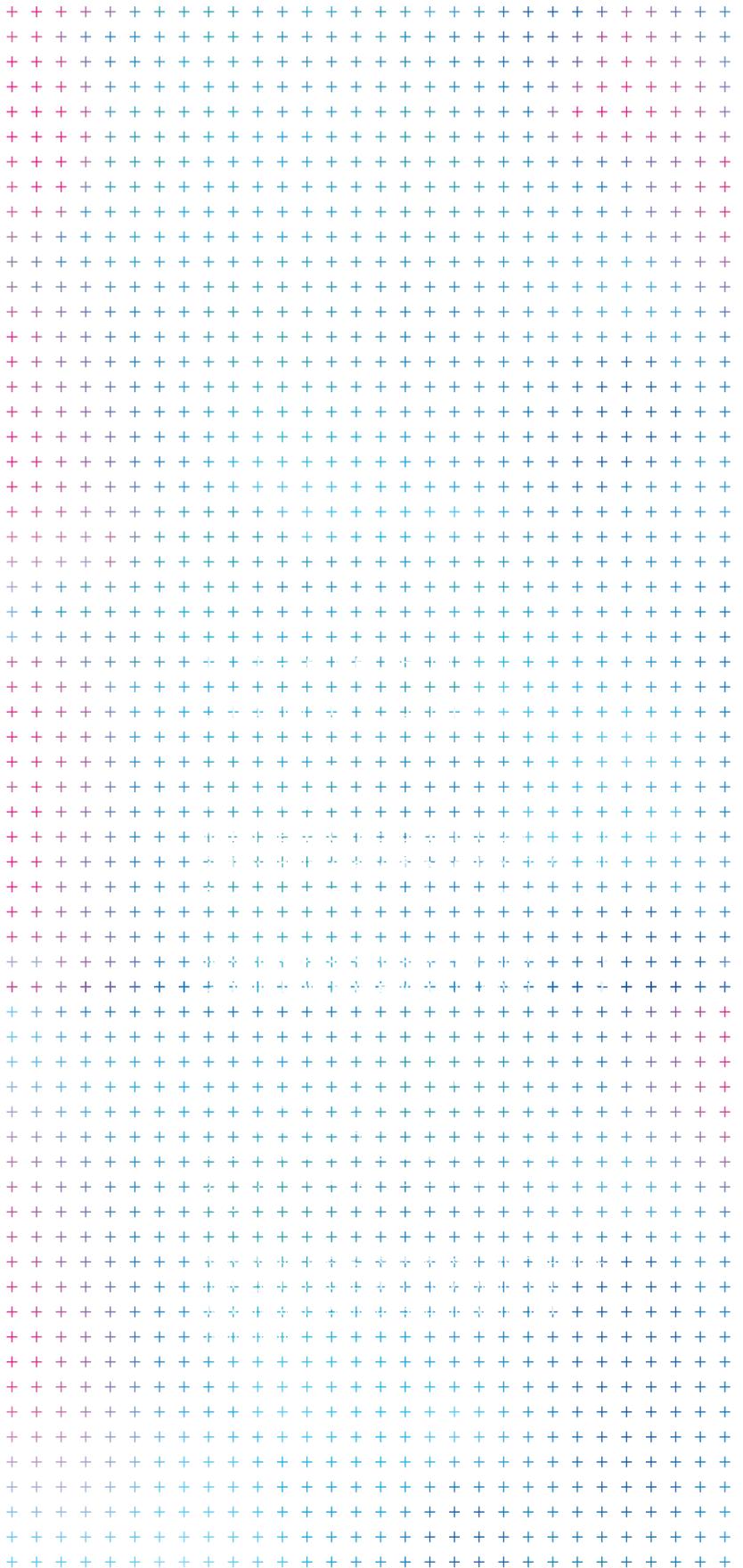
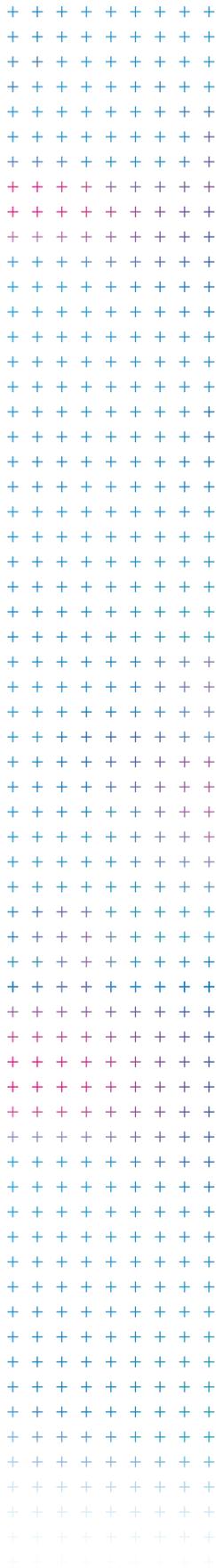
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