

Research Project:

Living with dementia and connecting with nature – looking back and stepping forwards

Exploring the benefits of green exercise with people living with dementia

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¹ www.greenexercise.org

² www.cloresocialleadership.org.uk

³ www.thewidespectrum.co.uk

⁴ www.thehearth.org

⁵ www.kcl.ac.uk

⁶ www.chalfontdesign.com

⁷ www.lboro.ac.uk

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dementia adventure

Neil Mapes



The author has a background in Clinical Psychology and has volunteered and worked in a wide variety of health and social care positions since 1994.

He has led and established a variety of innovative projects and initiatives including one of the first Alzheimer's cafés in the UK, a specialist outreach service for younger people with dementia, new qualifications in mental health, mental capacity advocacy, and multi media research into the social exclusion of older people.

He has provided dementia care training in a variety of settings, spoken at national conferences, featured on local and national radio, presented and facilitated workshops and seminars on a range of topics related to older people's mental health and mental capacity. He has written (and contributed to) various articles and reports on dementia, advocacy, mental capacity and mental health issues and is on various national advisory groups and boards including the editorial board for the journal 'Working with Older People'. Neil is a 2010 Clore Social Fellow, an UnLtd awardee and a Visiting Fellow at the University of Essex.



Neil Mapes and Dementia Adventure CIC

Dementia Adventure Community Interest Company (CIC)

Dementia Adventure was established in 2009, and provides adventure travel and short breaks for people living with dementia. It is also a leading voice in a social movement which is positively re-framing dementia. Dementia Adventure has a vision of society in which people live well with dementia, are connected to nature, and enjoy a sense of adventure. A society where people enjoy a full range of activities, have strong relationships with people in their communities and have access to places connected to their interests, passions and dreams. In addition to providing a range of local, national and international adventures Dementia Adventure also provides training, consultancy and research with individuals and organisations who wish to enable people to live well with dementia.

Dementia Adventure is a community interest company, which means it operates for the benefit of the community rather than for the personal gain of those involved. Neil Mapes, founder, and a Director of Dementia Adventure won a social entrepreneur award from UnLtd (www.unltd.org.uk) to develop his ideas with Dementia Adventure.

For more information on Dementia Adventure CIC, please call 01245 269 769 or visit the website www.dementiaadventure.co.uk.

Research background

There is an implicit feeling or sense that getting out into nature is a good thing for all of us and that this may have particular benefits for people living with dementia. Yet little is really understood about the sensory experience for people living with dementia connecting to nature and how this may help maintain their sense of self.

This research is based on the timescale of looking back 5 years and looking forward 5 years. What evidence and studies have been conducted since Dr. Chalfont published his bibliography paper in 2005? What will the next five years (life after the dementia strategy) hold for research in this area? And what do we know about the sensory experience (and importance) for a person living with dementia accessing and having connection with nature?

The aims of the research were:

- To better understand what is meant by the term 'living well with dementia'.
- To explore, collate and share research literature from the last five years to explore the benefits of green exercise for people living with dementia.
- To identify potential directions for research in this area in the next five years.

This research examined two questions:

1. Does green exercise enable people living with dementia to feel well and experience a temporary reduction or absence of dementia related symptoms?
2. Can walking outdoors help people living with dementia to positively re-frame their identity and self worth?

Context of research

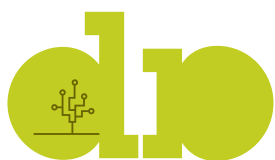
This research has been funded by, and should be considered in the context of, the Clore Social Leadership Programme.

The Clore Social Leadership Programme (CSLP) is an initiative of the Clore Duffield Foundation. The programme aims to identify, connect and develop aspiring leaders in the third sector. The Fellowship began in October 2009 and concludes for the author in March 2011. During this time the following general elements make up the "active programme":

- 360 degree review
- Residential weeks
- Action learning sets
- An extended secondment
- Coaching and mentoring
- Training courses
- A practice-focused research project

This research project is a relatively small yet important element of the CSLP programme. The research element has been included in the programme so that fellows gain understanding and insight into commissioning and using research in practice and to further their work in the third sector. It is not necessarily intended to be lengthy or formal in the academic sense but nevertheless an opportunity to capture and contribute knowledge and share this learning.

As the research proposal developed it became clear, following an introduction to the work with green exercise at the University of Essex, that an academically supervised piece of research would be conducted to optimise impact and to increase the opportunities for learning across social care and academia respectively.



dementia adventure

Literature scoping study

- There is a well-proven bank of evidence which informs our intuitive notion that “nature is good for us”. However, much of the literature regarding people living with dementia benefiting from nature is not peer reviewed with a lack of large randomised control studies (seen as the “gold standard”)
- Whilst there is strong and increasing evidence on the benefits of green exercise, until now the term green exercise (and research topic) had not been meaningfully linked with dementia.

- There has been much progress from some practitioners and researchers in the last five years in terms of understanding how activity out in nature can benefit people living with dementia and compelling anecdotal evidence that more can be done.
- However, there are still significant gaps in our collective knowledge, particularly in how green exercise and connection with nature affects people living with dementia at the earliest stages of the illness, whilst they are still living in the community.

Anecdotal evidence

- The simple act of walking is important in enabling us to feel well, to forget about the illness, and remain active.
- There are individuals who want to help create a more positive image of what it means to live well with dementia and want to re-frame dementia in their own minds as well as in others.
- Being out together in nature is something which many people living with dementia enjoy sharing in the moment.

Key findings

This research was a multifaceted project. Key findings are detailed for each element of the research as well as overall conclusions.

1

Green exercise is defined as: Engaging in physical activity whilst simultaneously being exposed to nature. **How aware were you of the term ‘green exercise’ before receiving this questionnaire?**



■ Never heard of it
■ Heard of it but not sure what it meant
■ Heard of it and knew what it meant

Walking interview

- Green exercise can enable individuals living with dementia to feel well and experience a “dampening down” or absence of their dementia related symptoms.
- The walking interview method could be something which is incorporated into many more research studies, particularly related to green exercise and dementia, because it locates the language of people living with dementia in the environment of interest.

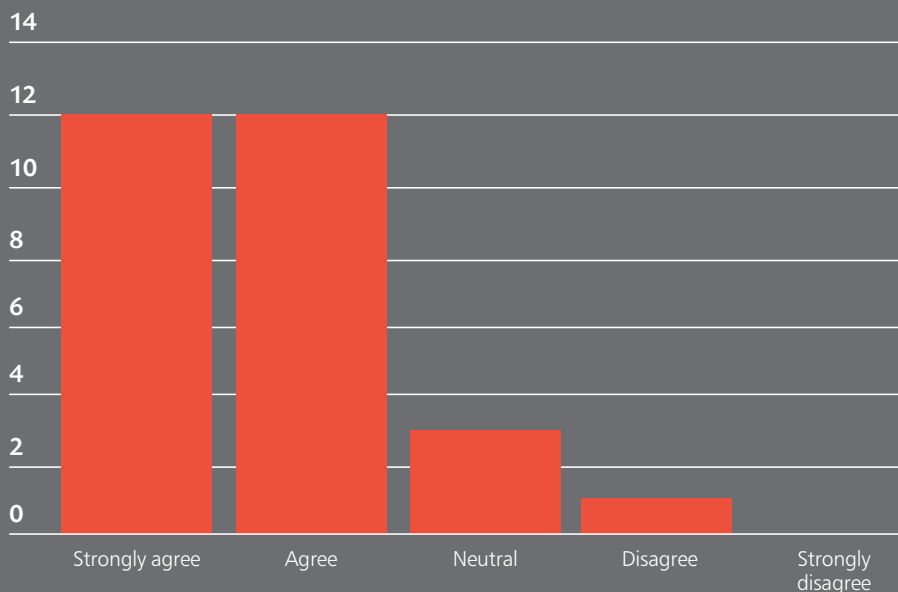
Experts survey

- 82.2% of experts surveyed agreed, or strongly agreed, with the statement “Human well-being depends on contact with nature”.
- Whilst there is a strong and increasing bank of general evidence on green exercise, until this research the phrase “green exercise” had not been meaningfully linked with dementia. More awareness of this phrase and the benefits is needed.
- 50% of respondents were aware of the term green exercise and knew what it meant, with 35.7% having never heard of it.
- 86% of respondents either agreed or strongly agreed with the statement: “As the progression of dementia advances there will need to be a proportionate increase in the support and facilitation on offer to enable all people living with dementia to benefit from green exercise”.

- Larger more scientifically robust studies are needed which demonstrate the efficacy of green exercise in promoting well being and extending the period of independent living for people with dementia.
- We need to learn more about the psychosocial benefits to people in different stages of the illness and living in different places, and the benefits this may have on family carers.
- There are many questions research still needs to address in this area including: what determines the extent to which people living with dementia can benefit from green exercise? What are the main opportunities and barriers to green exercise? Do different types of green exercise have different benefits? This area feels ‘uncharted.’ Only now are we beginning to recognise the importance of exercise and physical activity for physical and mental well being for all people (including people living with dementia).



How strongly do you agree or disagree with the following statement: ‘As the progression of dementia advances there will need to be a proportionate increase in the support and facilitation on offer to enable all people living with dementia to benefit from green exercise’





1 Key Findings

Experts survey (continued)

- There is little investment in green exercise areas even though the evidence of the benefits is compelling.
- The top three priorities for research in the area of green exercise and dementia identified by this research are:

1. Asking more people living with dementia (and their carers) how they live their lives, how to live a good life and the impact of green exercise on this.
2. Clarity on which forms of green exercise are the most effective with different levels of ability, including the costs and benefits of these forms of green exercise.
3. Impact of green exercise programmes in care homes.

Overall conclusions

- There is a fundamental and ancient connection we all have with nature and a strong sense of place, and this emotional connection with, and need for, nature remains present in the dementia process.
- Living well with dementia is a term we are beginning to better understand. Living well will depend on regular contact with and connection with nature.
- All people with dementia should have the opportunity to experience the benefits of contact and connection to nature whilst participating in exercise which adapts to their level of ability.
- The link between physical exercise and preventing dementia is only just beginning to be developed. Recent research publications by Dr. Erickson and colleagues from the University of Pittsburgh should encourage others to further develop well designed trials.
- The three future research priorities identified by this research need aligning with the recent government announcement that there will be more dementia funding available via the NHS National Institute of Health Research. These priorities will also need widely sharing and promoting if we are to gain a deeper understanding of the specific benefits of green exercise with people living with dementia.

Introduction



2.1 Living well with dementia?

The origin of this research was the assumption that there is a fundamental need and desire for all of us to have contact with and connection with nature. There is a bank of evidence that confirms what we already know – that the natural environment is good for us (Mayer et al, 2009). Kaplan said that the natural world satisfies our need for contemplation, escape, restoration and distraction (Kaplan 1995).

The proposal for this research was formulated when the National Dementia Strategy (Department of Health, 2009) called “Living Well with Dementia” was one year old. Dementia is one of the most pressing problems within our society, with increasing numbers of people living with dementia (Alzheimer’s Society, 2007) yet we know relatively little about the specifics of what “living well with dementia” means, particularly with regards to contact with and connection to nature. There was therefore a need to collate and share the recent evidence and studies related to living well with dementia including those detailed in the grey literature where relevant papers may not have been peer reviewed or subject to the rigour associated with scientific research.

2.2 Key research elements

This research comprised the following four elements:

- A literature scoping review
- A review of narrative and anecdotal evidence
- A filmed “Walking Interview” case study
- An online expert survey

Key research literature published in a wide variety of sources over the last five years (2005–2010) was examined and collated. A collection of author generated narrative and anecdotal evidence was summarised, assigned themes and grouped together under the headings of: sense of place, green exercise, re-framing dementia, social capital and managing risk. This paper is also accompanied by a filmed case study of Brian and June Hennell which gives deeper personal insights into the benefits of green exercise for people living with dementia. Finally the research used an online experts opinion and analysis questionnaire to identify potential directions for research in this area for the next five years (2011–2015). Key findings for people living with dementia and their carers, practitioners and researchers are drawn from all four elements of this research.

2.3 Intended Outputs

This research has been an opportunity to capture learning and both contribute to and share this learning with a wider audience. The research originally had three intended outputs:

- Published article – in at least one journal, (the Journal ‘Working with older people’)
- Filmed case study – of a walking interview with a person living with dementia engaging in green exercise
- Film and research launch event – during the Clore Social Leadership active programme year.

3 Literature scoping review – the evidence base

3.1 Introduction

A scoping review was used as the basis for conducting a review of recent relevant studies and articles relating to 'connection with nature' and dementia from 2005–2010. These years were selected for three reasons. Firstly, Dr. Garuth Chalfont published an extensive and very relevant bibliography in 2005 concerning dementia and connection with nature (Chalfont, 2005). Secondly, because this research element, and the research overall, had to be time defined to be delivered as part of the Clore Social Leadership Programme. Thirdly, the national dementia strategy (a five year strategy) was launched in February 2009 and was a year old when this research proposal was outlined. To address issues of relevancy and practicality the research was focused on a five year time scale, reflecting back on the last five years and looking forward five years. The objectives of scoping the literature were:

- to gather, collate, summarise and disseminate research findings
- to identify research gaps in the existing literature

3.2 Methods

The scoping review of the literature was conducted in 5 stages:

- Identifying the research questions
- Identifying relevant studies
- Study selection
- Charting the data
- Collating, summarising and reporting the results

Whilst these stages were helpful, the scoping review in practice followed an iterative model rather than a linear route. The scoping review was both library and desk based with the following libraries accessed as part of the review:

- Kings Fund library
- Centre for Policy on Ageing
- University of Essex

The research questions were formulated after compiling the literature review and collating the narrative evidence. Relevant studies were selected if they covered both aspects of dementia and nature and had been published between the years of 2005 and 2010. There was no restriction made with regards to the type of publication for selection.

The author invited interested parties (including experts and research supporters) to submit relevant studies for inclusion in the research. This 'snowball sampling' strategy was successful in identifying various papers, for example Dr. Joe Sempik in particular was helpful in sharing a bibliography list, Dr Gemma Jones shared published articles and Dr. Garuth Chalfont was similarly helpful in giving some further detail on his work with nature and dementia. The review was strictly time limited in order to deliver the research within the CSLP active programme year and so some studies or publications may have been missed. The review identified 40 studies, including journal articles (both peer reviewed and non-peer reviewed), chapters in books, organisational and departmental reports and discussion papers. The 40 studies were then summarised and individually subjectively ranked depending on which themes (tabled below) of "green exercise and dementia" the author felt the work highlighted. The data was collated, coded and summarised as a database of evidence used as a basis for the journal article *"It's a walk in the park – exploring the benefits of green exercise and open spaces for people living with dementia"* (Mapes, 2010).

3.3 Results

The scoping review identified 40 relevant published studies and articles concerning “green exercise and dementia”. The table below shows how many of the 40 articles addressed each of the themes, for example 16 out of the 40 articles addressed green exercise. The complete list of 40 articles adapted from the research database can be found in Appendix A.

3.3.1 Benefits of green exercise for dementia

The University of Essex defines green exercise as “*engaging in physical activity whilst simultaneously being exposed to nature.*” It is well known that exposure to natural places leads to better mental health whether it be a view from a window (Ulrich, 1984), being in nature (Pretty et al, 2005), or exercising in these spaces (Pretty et al, 2007). There are clear benefits to green exercise for a wide variety of people, these benefits include improved self esteem and improved mood, and often these benefits can be experienced from as little as five minutes in nature (Barton and Pretty, 2010). The University of Essex has published a range of papers⁹ on green exercise.

The Mental Health Foundation’s report “Moving on up” identifies the following advantages of exercise: exercise is cost effective, is available, there are co-incident benefits (e.g. healthier muscles and joints), is sustainable, promotes social inclusion and is popular (Mental Health Foundation, 2009). In addition most of us are never far from nature or from green spaces. The Woodland Trust’s Visit Woods project estimates that 33 million people in the UK live within 4km of a large wood that welcomes visitors (Woodland Trust, 2010). Often these spaces are cost free and don’t have opening and closing times. Increasingly, organisations such as Natural England with their *Walking for Health Initiative*¹⁰ and their campaign *Our Natural Health Service*¹¹ are encouraging everyone to make use of their local green space and the benefits this brings. *Walking for Health* are volunteer supported walks which people can join bringing the additional benefit of meeting and talking to new people, re-establishing community connections and peoples capabilities to support one another (outside of formal service provision).

Examples of current knowledge

Dr. Chalfont found that nature based experiences were therapeutic for people living with dementia. They were restorative or healing, contributing to the emotional, psychological and spiritual intangibles of well-being (Chalfont, 2006). Edward Wilson, back in 1984 (Wilson, 1984), used the term biophilia (literally a love of living things) and proposed the possibility that the deep affiliations humans have with nature are rooted in our biology. More recently, Professor John Zeisel says in his book, “I’m Still Here”:

“It is likely that the need for contact with the natural environment and the feelings we have about nature and being outdoors are hardwired, partly because this is a source of food. Sunshine, flowers, shade, moonlight and trees are all so much a part of our basic nature that no one has to be taught to respond appropriately to such stimuli. Again not surprisingly, gardens and nature are much appreciated by those with the illness.” (Zeisel, 2009, p.62)

Appendix A

Green exercise and dementia: subjective ranking of themes	Frequency of occurrence across the database
Sense of place	7
Green exercise	16
Well being	17
Symptom reduction	16
Re-framing	5
Self identity	4
Self worth	4
Sensory	5
Joy/pleasure	4
Social capital/networks	5



3 Literature scoping review – the evidence base

Exercise is one of five factors which has a strong evidence base for reducing the risk of dementia (Bradley, 2010). Studies which have concentrated on green exercise or activity with people living with dementia have shown that there have been improvements for people living with dementia in terms of better sleep patterns (Brooker et al, 2007), longer sleep duration (Connell, 2007), better continence, mobility (Brooker et al, 2007) and eating patterns (De Bruin et al, 2010). Connection to nature can enhance verbal expression in people living with dementia (Chalfont, 2006). Chalfont identified in the same research that nature based activities for people living with dementia can bring joy and sensory stimulation. He also found that family and professional carers play an important role in enabling a person living with dementia to maintain a connection to nature by overcoming obstacles (Chalfont, 2006).

Some of the emerging evidence includes green care (Sempik et al, 2010) and green care farms, and Dr. James Warner's research, which is a randomised control evaluation of walking as an exercise for people with dementia as part of the EVIDEM¹² programme.

The literature database was used as the starting place for the author's recent publication which also highlights and shares a broad base of related evidence and resources in this area: *It's a walk in the park: exploring the benefits of green exercise and open spaces for people living with dementia* (Mapes, 2010).

This article explores the benefits of green exercise and open spaces for people living with dementia. These benefits are set within the existing general evidence base concerning well-being and connection with nature. The scale of the social, economic and demographic challenges are outlined to enable potential opportunities to be identified. The benefits of green exercise, contact and connection with nature and open spaces for people with dementia and the current research gaps are identified. A case study of Dementia Adventure is highlighted, as are implications for practice.

Gaps in our knowledge

Whilst the benefits of nature are at times intuitive and have been widely evidenced, we don't yet have a strong sense of how these benefits might apply to the wide range of people living with dementia. There is a case to be made that people living with dementia may have an equal or higher need for contact, connection and activity in nature than those who don't have dementia. Studies which involve contact, connection and exercise in nature involving people with dementia appear to be on the increase, but there are gaps in the evidence. For example, which form of green exercise might work best and why for people living with dementia? The research gaps have been acknowledged by others more widely, for example Joe Sempik's literature review of social and therapeutic horticulture for people with mental ill health found a "distinct lack of quantitative data or experimental studies" (Sempik, 2007). Work like that highlighted by Jones and Van der Eerden (2008) is important in demonstrating the complexities of people living with dementia positively benefiting from being active in nature.

They considered the visual perceptual considerations such as glare in bright sunshine, the potential illusion effects of shadows and reflective surfaces (Jones and Van der Eerden, 2008). To conclude, Jo Moriarty's quote from 2006 is still relevant in 2011:

"While progress has been made in terms of our understanding about the importance of outside spaces for people with dementia and of the benefits of being outside in terms of mobility, sleep patterns and well being, there is still much to be done." (Moriarty, 2006)

3.4 Conclusion

There is a well-proven bank of evidence which informs our intuitive notion that "nature is good for us". However, much of the literature in this area is not peer reviewed with a lack of large randomised control studies (seen as the 'gold standard'). Also whilst there is a strong and increasing evidence on the benefits of green exercise, until now the term (and research topic) had not been meaningfully linked with dementia. There has been much progress from some practitioners and researchers in the last five years in terms of understanding how activity out in nature can benefit people living with dementia and compelling anecdotal evidence that more can be done.

However, there are still significant gaps in our collective knowledge, particularly in how green exercise and connection with nature affects people at the earliest stages of the illness, whilst people are still living in the community.

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⁹ Available at www.greenexercise.org

¹⁰ www.whi.org.uk

¹¹ www.naturalengland.org.uk/ourwork/enjoying/health/ournaturalhealthservice/default.aspx

¹² www.evidem.org.uk

4

4.1 Introduction

The following evidence has been compiled as a “bank” of quotes from people living with dementia, anecdotal stories and poetry. The author established Dementia Adventure (a community interest company) in 2009 to provide adventure travel and short breaks for people with dementia and to enable people to re-connect people with nature and a sense of adventure. The author’s recent work with Dementia Adventure, including a park walks programme, has informed this evidence as well as data gathered across many years by the author.

When considered together, these build a narrative around people with dementia connecting with nature. Key themes are identified, grouped into five headings with supplementary anecdotal evidence to support these groupings.

4.2 Methods

The information was transcribed (and anonymised) both from memory, original notes and other materials made by the author. The material was then examined and coded for key and recurring themes, a commonly used approach in analysing qualitative data such as these. Themes were subsequently sorted into five groups to focus on particular aspects of dementia and nature. The method used here is based upon meta-analysis, trying to systematically make sense of a large bank of material. In this case the majority of the material had not been previously captured in writing. This approach also was helpful in generating the specific research questions, which emerged from both the literature and the narrative evidence.

4.3 Results

The following narrative and anecdotal evidence represents relevant information gathered over the last 16 years by the author and summarised here for the first time. Themes are first summarised and detailed individually with evidence.



Narrative and anecdotal evidence

4 Narrative and anecdotal evidence

4.3.1 Summary and grouping of key themes

SUMMARY OF KEY THEMES	
Walking	Need for nature
Thriving	Flexibility
Symptom reduction	Choice
Recovery	Friendship
Positive risk taking	
Solidarity	
Safety	
Activity	
Free exercise	
Loss	
Sensory and emotional memory	
Permission	
Landscape	

In order to start making sense of the key themes I have grouped them together under five headings as follows, which are further supported by evidence.

Grouping A:	Sense of place
Themes:	Sensory and emotional memory, need for nature, landscape
Grouping B:	Green Exercise
Themes:	Walking, activity and free exercise
Grouping C:	Re-framing dementia
Themes:	Thriving, symptom reduction and recovery
Grouping D:	Social capital
Themes:	Positive risk taking, choice, friendship and solidarity
Grouping E:	Managing risk
Themes:	Safety, loss and permission

4.3.2 Grouping A: Sense of place

Themes: Sensory and emotional memory, need for nature, landscape

These themes are all linked to a deep connection we have with nature, with the physical landscape around us, our sense of place in it and with our deepest memories of being in nature. There is something about our need for nature being “hardwired” into the biology of the brains connected to our evolutionary history from this quote from John Zeisel:

“It is likely that the need for contact with natural environment and the feelings we have about nature and being outdoors are hardwired, partly because this is the source of our food. Sunshine, flowers, shade, moonlight, and trees are all so much a part of our basic nature that no one has to be taught to respond appropriately to such stimuli.”
(Zeisel, 2009, p.62)

Dementia Adventure CIC and Innovations in Dementia CIC teamed up to provide a day out to Standen National Trust (see appendix C). People living with dementia were asked “What makes a good day out?” The need for nature and the sensory experience of nature’s beauty is captured in the replies:

“Getting out into nature”

“It’s a unique place very beautiful.”

The following poem by a person living with dementia, simply titled *Grass* and kindly shared here by John Killick (Killick, 1998), captures the deeply emotional memories which often remain intact in the dementia process. These are physical and sensory memories connected to being outdoors in the fresh air and lying in the grass.

Poem by Dora – person living with dementia

Grass

A young fella carried me
in here; it were a long way
and a long time ago.
I were lying on grass...

I dont want to stay, no
there's nothing for me
they're all very kind
but i dont want to be

inside anywhere at all
it's much too hot and bright
it just dont feel right
I've not been used

I need the fresh air
I keep calling out:
Nurse, Nurse, carry me
outside to where

I were lying on grass.

4.3.3 Grouping B: Green Exercise

Themes: Walking, Activity and Free exercise

These themes are all centred around the importance of exercise out in nature, being active, feeling well and enjoying the specific activity of walking. People want to remain active, and walking is a cost free way of doing so. The act of being out walking in the hills is related by one gentleman living with dementia as a natural high. As part of the author's work with Dementia Adventure, people who are keen walkers have come forward including a man with dementia telling me about his regular walks along the trails near his home; a keen walker and cyclist in the rural lanes of Sussex, and another man who takes daily three hour walks around the fields near his home in Essex.

Walking was a key recurring theme within the narrative evidence as illustrated by case study 1 in Appendix B, simply summed up by this lady living with dementia:

"It's about exercise and beauty isn't it?"

The Innovations in Dementia Walking group, detailed in Appendix D, captures some wonderful quotes from people living with dementia whilst out walking including:

"I still get down times, but I get up times, like this today [walking in the hills near Swindon] I'll be on top of the world when I get home."

"The way I've tried to get round it is going for walks...I've been to places I wouldn't have seen in a normal life."

"I'll get up and have breakfast and walk into Swindon, which'll be about an hour, go to the library and read the papers. One, I'm cutting my expenditure down, secondly I'm getting exercise."

4.3.4 Grouping C: Re-framing dementia

Themes: Thriving, symptom reduction and recovery

The act of being out in nature can make the symptoms of dementia, for example memory loss, less obvious and less of a focus to the individual with dementia and to others around them. There can be a very important re-discovery or "recovery of self" when confronted with dementia. The typical cognitive symptoms of decline one might normally expect to see with regards to memory and attention were not as obvious out in nature, partly due to the environment and activity being one which is emotionally engaging. People living with dementia can thrive when out in nature as can be seen in the following quote:

"It's the brightest I've seen my mother for a long time." – family carer quote from case study 1 in appendix B

The following quotes taken from people living with dementia taken from case study 2 in appendix C:

"When you are with interesting people, the Alzheimer's goes."

"You know when we do these things I forget I've got dementia"

"When you get a diagnosis of dementia, you can't get your life back. But you can get a new life."

Case study 3 also enables us to hear some significant narratives linked to recovery of self:

"Life doesn't just end because you got dementia."

"My life is positive. It wasn't when I first got diagnosed, but it is now."

"When you get diagnosed with dementia or Alzheimer's you wake up and look at it, it's another part of the adventure in life and you go on from there rather than hiding away."

4 Narrative and anecdotal evidence

4.3.5 Grouping D: Social Capital

Themes: Positive risk taking, choice, friendship and solidarity

These themes all reflect that there is a sense of a growing movement and individual stories are emerging where people are taking risks, want more real choices in their lives and want to stand along side each other in living better lives. Some of the following all took a number of positive risks with, for example June (below), planning meticulously to mitigate the risks. Often the negative experiences they expected to have to deal with, such as anxiety in new places, didn't materialise. Indeed the person living with dementia was thriving from the benefits of being out with friends in nature and having a sense of adventure. Once again the Dementia Adventure case study 1 in appendix B highlights this positive approach from people living with dementia:

"Thanks for being brave and taking this on" – gentleman living with dementia

Case study 2 provides us with further insight into taking positive risks and enabling friendship too:

"Going as a group can make you feel safer"

"Having support from someone you know well"

The following individual stories highlight the themes further:

- A gentleman called Richard who has voluntarily supported 3 couples living with dementia in his neighbourhood to spend a week together in the sun in Marbella in Spain. Richard first did the trip with one couple, then two and then another year with three couples (some of whom have physical disabilities too).
- A man living with dementia recounting his recent trip to India where he met tigers in the wild. He recounted, *"We watched the tiger leap down onto a hot rock and sit there majestically in the sun."* He and the others watching this event simultaneously burst into tears. Upon recounting this story to me he also started to weep.
- A couple living with dementia who recently returned from a month long adventure 'down under' visiting family in Australia and touring around the coast.

- A couple living with dementia who have just come back from a group holiday in India and are now independently travelling to South Africa. June prepared meticulously for the trip, including devising her own 10 point 10 question well-being scale which she went through each day with her husband Brian. During the three week break, Brian's well-being score never went below 8.5 out of 10 (10 being excellent on her scale). This "high" lasted three days after they got home and then a period of "down time" happened when they both were aware that they were back in the normal routine again. So they started planning another trip (to South Africa) and Brian's well-being lifted again at the thought of another trip. Other holiday travellers on the India trip commented:

"You would never know he had dementia"

"It has been a privilege to share two weeks with you both"

"You have changed my outlook, I realise now my view of dementia was so negative."



• Amy Jones and Ruth

A number of stories are emerging nationally where people living with dementia are being enabled, via a new system of social care payments called self directed support, to live life the way they choose. One example is the story of Amy Jones and her mother Ruth on the Cumbria City Council website.

Amy's mother has Alzheimer's disease. It was not until the sudden death of Amy's father that the family began to find it difficult to provide the daily care Ruth needed. Amy and Ruth were offered direct payments. With these payments they paid a local carer who had been recommended to them. Despite her condition, Ruth still had a passion for wildlife and walking which she shared with her carer. Over the subsequent two years the friendship between the two women blossomed and they would visit local open gardens, enjoy walks in the Lake District, bird watch and have afternoon tea together. Direct payments helped Ruth enjoy her final years of life to the full.

A number of themes emerged for me from Amy's story which again highlights our desire and need to walk, but to share this with others and to have choices and flexibility about what we do. Finally the following quote, taken from case study 3 in appendix D about the 'united front' sounds like a call to arms and a call for solidarity for people with dementia.

"Regardless of whether it's Parkinsons or whether it's Alzheimer's or whether it's one of the other, of the many, we need to pull everybody together like a united front."

4.3.6 Grouping E: Managing Risk

Themes: Safety, loss and permission

People often described their fears as highlighted in case study 2:

"I got the fear. When I go away from my local area, it's a panic, a blank."

The risks of going out can be mitigated by going to "safe places" and having "safety in numbers" as highlighted above. These risks should also be considered in the context of the potential benefits an individual may gain from any given activity out in nature. This is particularly important when the "re-discovery of self" may be the benefit of walking, for example. Yet older narrative still persist, as highlighted below (quotes captured from 2000–2002) and detailed in appendix E, captured from people living with dementia at a day centre, they reflect a powerful sense of loss:

"Somebody has pulled the plug on my life."

"My memory is shocking and I know I won't be able to keep up with people and it's disappointing."

"I was the brainy one, it's melted now, it's melted my heart."

There is also an important related theme here that people living with dementia often don't have the "permission" to go out like others can, as highlighted by the following quote taken from appendix C:

"My family clamped down on me going away on holiday. It feels like you are in prison."

4.4 Conclusion

The information captured here is a starting place when considering "what I already know" about people living with dementia getting out into nature and being active. But it is an important pointer for the other three phases of this research, these being literature scoping review, experts questionnaire and walking interview.

By grouping the themes I can begin to see how there is a fundamental and ancient connection we all have with nature, and a strong sense of place within the landscape. Perhaps unsurprisingly the emotional connection with, and need for, nature remains present in the dementing process. But the importance of the act of walking in enabling us to feel well, to forget about the illness and remain active cannot be understated. This in turn is linked to a growing sense that there are individuals who want to help create a more positive image of what it means to live well with dementia and want to re-frame dementia in their own minds as well as in others. Being out together in nature is something which many people living with dementia enjoy sharing in the moment.

Case study: Brian and June – a walking interview

5

5.1 Introduction

Brian Hennell is living with dementia and is being supported by his wife June. Brian and June heard about the research and the work of the author via another organisation (Innovations in Dementia CIC) and self-selected to be part of the research and agreed to be filmed taking part in the “walking interview.” This case study method (Clark and Emmel, 2008) allows for a deeper connection with the importance of green exercise for people living with dementia. By capturing Brian’s experiences and comments on film, we can directly connect with the benefits in particular for Brian when he is out on his walk.

A semi-structured interview approach was chosen containing questions to ask the walking interview participant whilst walking out in nature. The interview set of questions can be found at appendix F.

The interview took place once approval had been given by the University of Essex Ethics Committee, after full information had been given to the participant verbally and in writing and once their consent had been given. This consent included the filming of the walking interview and the sharing of this film for educational and promotional purposes.

5.2 Methods

John Zeisel describes the objectives of “focused interviews” (Zeisel, 1984) as:

- Definition of the situation – the way the individual sees and interprets the event influences the way she responds to the event.
- Strength of respondent’s feelings – what is most important for the individual.
- Intentions – by asking about intentions we can distinguish between intentional and unintentional consequences of behaviour and events.

Andrew Clark and Nick Emmel (ESRC national centre for research) describe “walking interviews” as participatory social mapping and day diaries used alongside quantitative and qualitative data (Clark and Emmel, 2008).

They talk of the:

- Significance of route – places of belonging, places of avoidance
- Importance of “neighbourhood infrastructure” – shops, cafes, pubs
- Local geographies of social networks – friends houses, neighbours and familiar strangers
- Significance of place – as relational, as networked, as biographical
- Places and practices – everyday (walking through), extraordinary (significant to time, memory and geography)

Phil Jones et al in their 2008 article "Exploring Space and Place With Walking Interviews" is a very good place to start for researchers considering this method. They highlight how few projects have *"attempted to rigorously connect what participants say with where they say it,"* (Jones et al, 2008)

Brian and June consented to be participants in the study and for their experience to be filmed and shared to promote a better understanding and awareness of dementia and the benefits of green exercise. Brian and June were both given detailed information verbally and in writing about the research and consented to take part in writing.

An independent film maker was commissioned to film, edit and produce a short film capturing the walking interview. A set of questions were formulated based upon emergent themes from the research. These were developed to deepen our understanding about the different elements of green exercise for Brian and the particular benefits this brings him as a person living with dementia.

The author, participants and filmmaker had never met each other or worked together before the day of filming and only had one day in which to complete the filming.

Issues about method:

- Weather– capturing a clear day for filming with good light levels is important when trying to maximise the effects of being in nature. The day of the filming was a mixed day of weather with rain, sun and clouds all making filming difficult.
- Anonymity – being seen with a research interviewer and filmmaker out on the walk could be problematic – a quiet rural location with views was selected for this reason.
- Control – we made every effort to ensure that the participant controlled the research encounter as much as possible and he took his "normal walk" out in nature.

5.3 Results

The filming itself took place in one day in late July 2010 in the garden at Brian and June's home and out on one of Brian's favourite walks along the canal. Luckily there was a small episode of good weather in the day for filming and the afternoon along the canal path proved to be sufficiently quiet to allow for filming. The film of the walking interview with Brian and June Hennel accompanies this report.

The full length film is available on line at www.dementiaadventure.co.uk

5.4 Conclusion

Brian and June have watched their film a number of times. They are struck by how laid back they appear on film. Crucially, they share a number of unique insights into why green exercise is important to them with Brian informing us on film of how his daily walk "dampens down" his dementia related symptoms.

This element of the research presented most risk in terms of what could go wrong, particularly given the working constraints of the filming. However, by successfully completing this element this research has shown that people living with dementia want to be involved in research and it gives unique and inspirational insight to this research topic. The walking interview method could be something which is incorporated into many more research studies, particularly related to green exercise and dementia, because it locates the language of people living with dementia in the environment of interest.

Future research needs – expert opinion analysis



6.1 Introduction

In order to establish the needs of future research, national experts from national statutory and voluntary organisations and local practitioner organisations were asked to take part in an online survey. Expert topics focussed specifically on dementia and/or green exercise. The aim of this approach was to reach a consensus view for future research in this area over the next five years.

6.2 Methods

Experts in the field were selected and individually invited by the author from national statutory and voluntary organisations and local practitioner organisations to take part in answering questions concerning the “next five years” and the preferable future for research in this area. The experts were selected on the combination of the following factors:

- they had published relevant research regarding dementia or green exercise
- they held an academic position of significance in this area of study
- they held a policy or practitioner position concerned with dementia or green exercise
- they had been highlighted by another expert as someone who should be included in this work

Over a matter of weeks from initially identifying 12 experts a list of 32 experts made up the selected “experts panel.” An online questionnaire was developed and used in consultation with experts based on the DELPHI method (Rescher, 1998). These people were then sent a link to a Survey Monkey online questionnaire, the first question of which concerned their informed consent to take part. For the full set of questions and summary responses see appendix G.

Snowball sampling was used to reach experts in the field with whom the author did not have previous connections or detailed knowledge of their work and thus widen the reach of responses. The web link was made “public” and so was capable of being forwarded on to other “experts” in the field by those identified originally, thus also increasing the scope for and chances of a higher response rate. The survey was “time-limited” and thus was “live” for responses between July 27th and September 10th to allow subsequent time to analyse the results. The results were then analysed using the supporting software which accompanies Survey Monkey. Results for question 11 have been included as direct quotes. Responses for question 13 (priorities for future research) were aggregated and ranked with a score of 3 points given to a topic rated as priority one, two points for priority two and one point for priority three. By scoring and aggregating the scores, three top priorities (the most popular when ranked) emerged for future research.



6.3 Results

6.3.1 About the participants

28 people agreed to be part of the research and filled out the on-line questionnaire.

Respondents included academic researchers (14) Senior health and social care staff (8) Policy staff in Charities (2) Architects (2) and others (2). Responses were from people with direct experience of managing and running services with people living with dementia, CEO's and deputy directors of charities, researchers with many years of experience including teaching and research management experience. Responses were received from people working across England, Scotland, the Netherlands and Australia.

6.3.2 Results of survey questions

Each of the data questions results are summarised and anonymised with additional comments detailed below, please see appendix G for a full set of questions used in the online survey and a summary of results data.

Question 3 Result: 82.2% of respondents agreed or strongly agreed with the statement "Human well-being depends on contact with nature:

Question 4 Result: 61% of respondents had contact with nature and green spaces three times a week or more.

Question 5 Result: 50% of respondents were aware of the term "green exercise" and knew what it meant, with 35.7% having never heard of it.

Green exercise is defined as: Engaging in physical activity whilst simultaneously being exposed to nature. **How aware were you of the term 'green exercise' before receiving this questionnaire?**



Never heard of it
Heard of it but not sure what it meant
Heard of it and knew what it meant

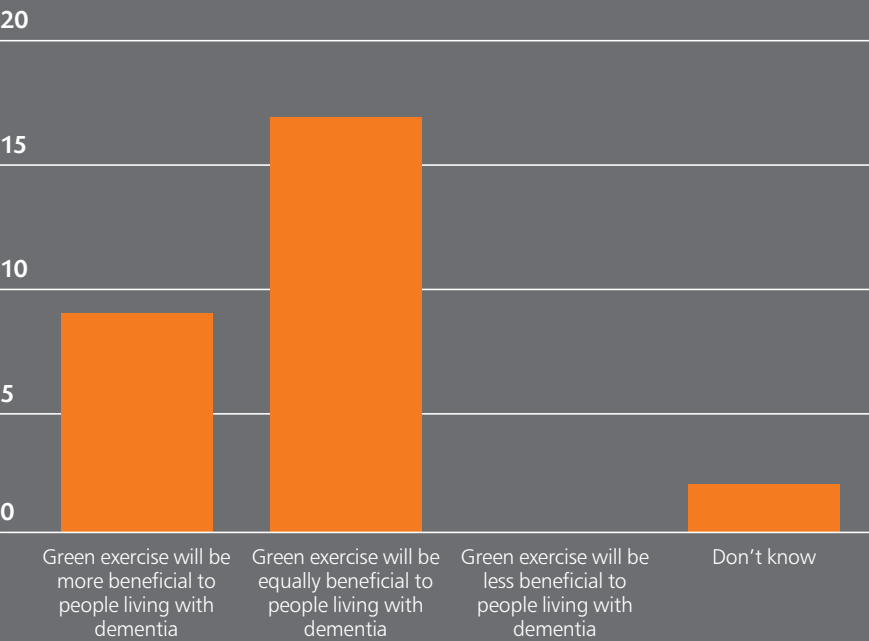
6 Future research needs – expert opinion analysis

Question 6 Result: 32% of respondents felt that green exercise will be more beneficial to people living with dementia, with 61% feeling it will be of equal value

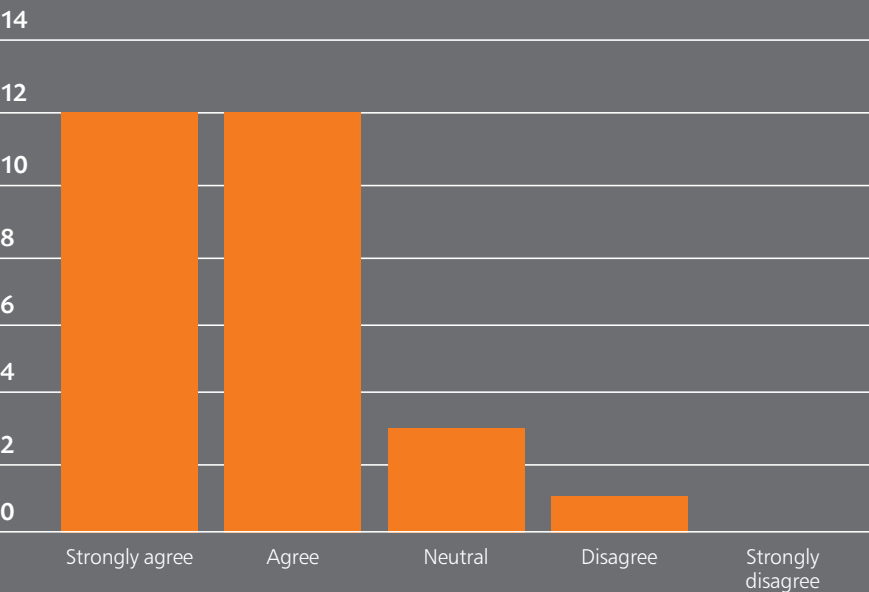
Question 7 Result: 86% of respondents either agreed or strongly agreed with the statement: “As the progression of dementia advances there will need to be a proportionate increase in the support and facilitation on offer to enable all people living with dementia to benefit from green exercise”

Recent research shows that green exercise is beneficial to mental well-being (for example improved self esteem and improved mood) for a wide variety of different people.

How do you feel the benefits of green exercise will apply to people living with dementia?



How strongly do you agree or disagree with the following statement: ‘As the progression of dementia advances there will need to be a proportionate increase in the support and facilitation on offer to enable all people living with dementia to benefit from green exercise’



20 Research Project:
Living with dementia and connecting with nature – looking back and stepping forwards

Question 8 Result: Respondents felt that green exercise would work best for “physically fit/able people” and “people living with dementia in residential/nursing care”, with all categories scoring highly:

Individual responses to question 8

“I think green exercise may be beneficial for all groups. However, people in the more advanced stages of dementia or those living in long term care institutions need more stimulation to participate in green exercise since they probably won’t go to green areas themselves.”

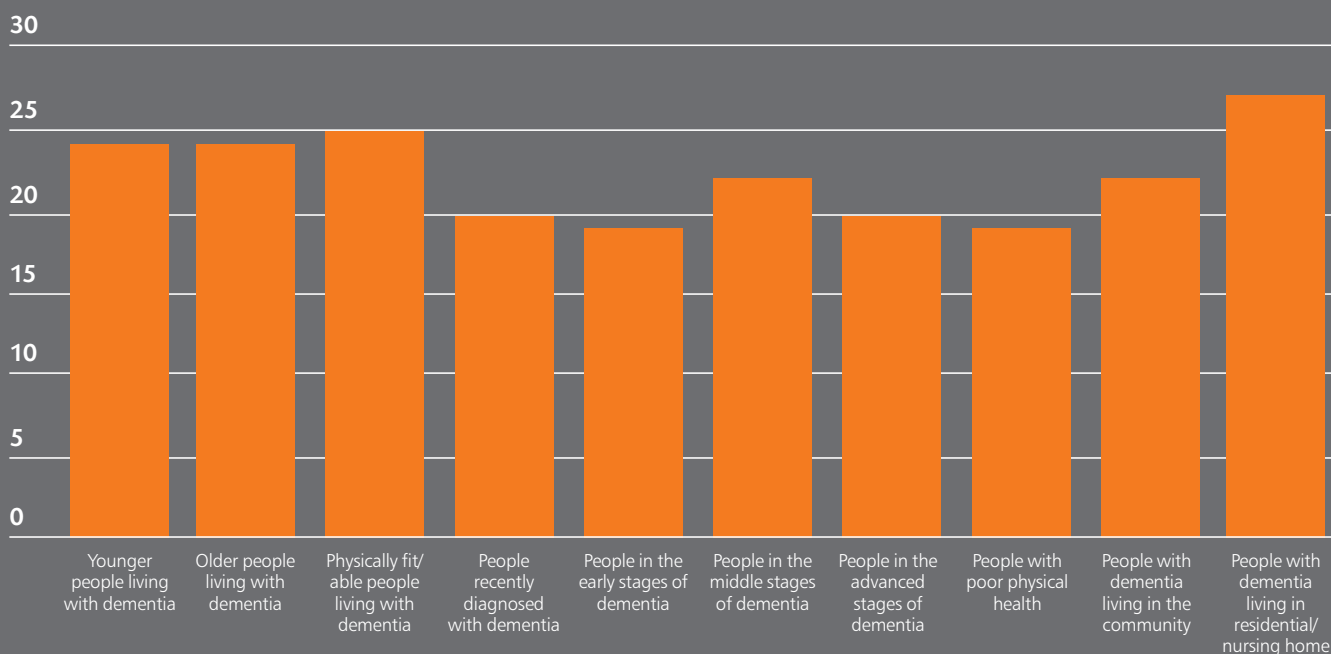
“Green exercise may be beneficial for different reasons for each of the groups. Activities such as gardening/horticulture may particularly be beneficial for patients in the early stages of dementia since

gardening is a possibility for them to participate in normal daily life. By participating in such activities they may show to others, that even though they have cognitive problems, [they] are still able to do meaningful/useful work which may benefit their self-esteem. Dementia patients in the more advanced stages of dementia are probably not able to participate in activities such as gardening but exposure to green areas (e.g. by taking a walk) may for them be beneficial in terms of, e.g. reminiscence, sensory stimulation, etc. which in turn may reduce behavioural problems.”

“I think all people with dementia should have the opportunity to experience the benefits of engaging with nature whilst participating in exercise which adapts to their level of ability.”



Which of the following groups might green exercise work best for? (please choose all that apply)



6 Future research needs – expert opinion analysis

Question 9 Result: Respondents largely used their own experience rather than literature or anecdotal evidence to base their opinion on the groups it might work best for:

Question 10 Results: Age was rated by 82% of the respondents as “not important”, much higher than the other factors when considering who might benefit most from green exercise



Question 11 Result:

Identification of research gaps

- Amount of research into green exercise is limited and the use of terminology varies thereby making research more difficult.
- The benefits of outdoor usage in relation to behavioural disturbances and medication usage.
- As I had not heard of this as a concept there needs to be more awareness for service providers and commissioners (particularly). However it all seems to make absolute sense!
- As I've never come across the term 'green exercise' I would imagine there are several important aspects of life with dementia that could be impacted by introducing such activity. It would be interesting to see the impact of green exercise on modulating symptoms both cognitive and non-cognitive; likelihood of moving into a care home, or indeed between care homes; impact on functioning, quality of life and carer burden/stress; mortality rates; and use of services. If it has a demonstrable positive effect, then investigating ways of delivering such a therapy would be important.
- Use of virtual green spaces/social media?
- The literature about green exercise is good but there isn't much of it unless you search. There is not much investment in green exercise areas even though the evidence of the benefits is compelling. Some areas may even be axed in the latest round of cuts!! My personal view is that researchers spend too much time looking for a cure than how a person with dementia could live a fulfilling life that is suitable to their personal preferences and lifestyle.
- Little seems to have been written about green exercise for people in the latter stages of dementia.
- Probably gaps in research for people in the early stages of dementia.
- Measurable outcomes of green exercise benefits compared to green isolated people within similar control groups.
- There is research out there but I found that it wasn't very robust, most things needed to be proved on a bigger scale. I would like to have solid evidence, not just anecdotal, that demonstrates the efficacy of green exercise in promoting well-being and extending the period of independent living for people with dementia.
- Studies that link the positive advantage with financial benefit to persuade the 'hard-nosed' developer of care homes that there is financial benefit in having healthier, happier and more physically able people with dementia as well as happier staff with less staff turnover.
- We need to learn more about the actual benefits to people in different stages and living in different places; the benefits this may have on family caregivers; the psychosocial benefits; improvements in sleep patterns, mood and appetite; the effects this may have in terms of medication reduction, improving balance and gait; reducing hospital visits and delaying institutional care.
- In depth exploration of the benefits, what determines the extent to which people with dementia can benefit? What are the main opportunities and barriers to green exercise? Do different types of green exercise have different benefits?
- It feels like an uncharted area. Only now are we beginning to recognise the importance of exercise and physical activity for physical AND mental well being for all older people including people with dementia.
- I am not aware of the research literature in this area so a current gap may be a brief overview of what the existing literature tells us. Do we know whether there is a difference in outcomes (in terms of well-being) between green exercise and any other activity which the person finds enjoyable and stimulating?
- 1. Lack of quantitative data – e.g. would be good to ask Q4 of the 820,000 people with dementia.
2. Identifying and overcoming barriers to people with dementia accessing green space
3. Can green exercise eliminate need/use of anti-psychotropic medication? (to establish this would be great, as green exercise might then be prescribed for pwd rather than toxic anti-psychotics).
- We do not know what works best for whom, and what the full range of benefits is.
- Scientific evidence for the beneficial effects of green exercise for dementia patients obtained from studies that have larger sample sizes than current studies.
- I think there is very little existing research on exercise in general and dementia – especially when compared with research on exercise and well-being in other groups, such as older people or people with depression. In addition, in dementia care, exercise can be seen as something quite negative that needs to be controlled – such as 'wandering'. There's also very little work on how people with dementia respond to the external environment – e.g. if being in a 'green' environment makes people feel better.

6 Future research needs – expert opinion analysis

Top three priorities for research in the next five years:

1: To ask more people living with dementia, and their carers, how they live their lives, how to live a good life and the impact of green exercise on their lives

2: Clarity on which forms of green exercise are the most effective with different levels of ability including the costs and benefits of these forms of green exercise

3: Impact of green exercise programmes in care homes

6.4 Conclusion

One of the important elements of this research has been the gauging of expert opinion on what research is needed in the future in this field. The online survey method was successful in reaching a relatively broad group of experts, with albeit a statistically low, sample size.

The participants themselves provided a wealth of data related to green exercise. Specifically, three priority areas clearly stood out from the priority suggestions received. These priorities now need aligning with the recent government announcement that there will be more dementia funding available via the NHS National Institute of Health Research.

These priorities will also need widely sharing and promoting if we are to gain a deeper understanding of the specific benefits of green exercise with people living with dementia.



Discussion

This research has formed one element of the author's 2010 Clore Social Leadership Programme. As such this work has been time-limited yet much has been achieved with this first, timely and meaningful attempt to link and study the topic of green exercise with people living with dementia. The multi-faceted nature of this research has brought together literature, anecdotal and case study evidence as well as gauging expert opinion on future research needs. There is a repository of recent literature, evidence, case studies and quotes which is supported by an inspirational case study captured on film.

There is a fundamental and ancient connection we all have with nature and a strong sense of place, and this emotional connection with, and need for, nature remains present in the dementia process. 'Living well with dementia' is a phrase we are beginning to better understand and living well will depend on regular contact with and connection with nature. All people with dementia should have the opportunity to experience the benefits of contact and connection to nature whilst participating in exercise which adapts to their level of ability. The three future research priorities identified by this research need aligning with the recent government announcement that there will be more dementia funding available via the NHS National Institute of Health Research. These priorities will also need widely sharing and promoting if we are to gain a deeper understanding of the specific benefits of green exercise with people living with dementia.

As this research started drawing to a close, walking and dementia began to make national and world headlines. The work of Dr. Erickson and colleagues from the University of Pittsburgh was widely covered by the world's media (New York Times, 2011) and has been extremely significant in identifying an optimum distance (9 miles a week) for "neurological exercise" and demonstrating that walking can increase the size of the hippocampus region of the brain and improve memory. Their research has also informed us that the brain is modifiable until late adulthood and that it is never too late to start exercising.

This research has meaningfully linked green exercise with dementia. The recent evidence from Erickson and colleagues is exciting and encouraging in equal measure. In 2011, with new government funding opportunities for dementia research, hopefully we will see the designing of further research studies which trial physical exercise and its benefits for different groups of older adults and those with different types and stages of dementia.

The simple regular act of walking together out in nature may yet be the strongest and most easily accessible treatment and prevention of dementia.



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9

Appendices

9.1 Appendix A: Green exercise and dementia database

The following 40 published articles have been shared here to assist other researchers examining the topic of green exercise and dementia. They compliment the references, although some are not referenced in the main text; they were collated within the time limited scoping review element of this research. It is worth noting that since conducting the scoping review Dr. Kirk Erickson and colleagues at the University of Pittsburgh have published two significant study results concerning walking and dementia.¹³

¹³ Papers available via: http://www.psychology.pitt.edu/people/faculty/faculty.php?fc_id=83

9.1 Appendix A: Green exercise and dementia database *continued*

Author	Date	Title
Tessa Perrin, Hazel May, Elizabeth Anderson	2008	Wellbeing in Dementia: an occupational approach for therapists and carers 2nd ed.
Ed. Julian C Hughes, Stephen j Louw, Stephen R Sabat	2006	Dementia Mind, Meaning, and the Person
Jo Barton and Jules Pretty	2010	What is the best dose of nature and green exercise for improving mental health? A multi study analysis.
Jules Pretty, Caroline Angus, Madeleine Bain, Jo Barton, Valerie Gladwell, Rachel Hine, Sarah Pilgrim, Gavin Sandercock, Martin Sellens	2009	Nature, childhood, health and life pathways
Rachel Hine, Jo Peacock and Jules Pretty	2008	Care farming in the UK: evidence and opportunities
SR De Bruin, SJ Oosting, H Tobi, YH Blauw, JMGA Schols, CPGM De Groot	2010	Day care at green care farms: a novel way to stimulate dietary intake of community dwelling older people with dementia?
SR De Bruin, SJ Oosting, Y Kuin, EM Hoefnagels, YH Blauw, LCPGM de Groot, JMGA Schols	2009	The Concept of green care farms for older people with dementia
DJ Brooker, RJ Woolley, D Lee	2007	Enriching opportunities for people living with dementia in nursing homes: an evaluation of a multi level activity based model of care
G Chalfont	2006	Connection to nature at the building edge: towards a therapeutic architecture for dementia care environments
G Chalfont	2008	Design for nature in Dementia care
B Connell and J Sanford and D Lewis	2007	Therapeutic effects of an outdoor activity program on nursing home residents with dementia.
M Calkins, J Sznerekovsky and S Biddle	2007	Effect of increased time spent outdoors on individuals with dementia residing in nursing homes.
K Diaz Moore	2007	Restorative dementia gardens: exploring how design may ameliorate attention fatigue
A Phinney, H Chaudry, DL O'Connor	2007	Doing as much as I can do: the meaning of activity for people with dementia
L Eggermont and E Scherder	2006	Physical activity and behaviour in dementia: a review of literature and implications for psychosocial intervention in primary care
S Arkin	2007	Language enriched exercise plus socialization slows cognitive decline in Alzheimer's disease.
G Chalfont	2007	The dementia care garden: part of daily life and activity

Author	Date	Title
E Rappe and P Topo	2007	Contact with outdoors greenery can support competence among people with dementia
J Burgess	2009	Sowing seeds: introducing the eden alternative
GMM Jones and WJ Van der Eerden	2008	Designing care environments for persons with Alzheimer's disease: visuoperceptual considerations
FS Mayer, C McPherson Frantz, E Bruehlman-senecal, K Dolliver	2009	Why is nature beneficial? The role of connectedness to nature.
C Bradley	2010	Risk factors for dementia
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9.2 Appendix B: Case study 1 – Dementia Adventure CIC

Case study 1:

Dementia Adventure organised three “Walk and Talk Together” events at Hylands House in July 2010. We were joined by members of the Alzheimer’s society mid-Essex branch and staff from Essex Dementia Care as well as being supported by the Mayor and Mayoress of Chelmsford who kindly attended our last event in July. In total 55 people attended the three events. We spent time walking in the beautiful pleasure gardens and one world garden:



We also spent some time talking together about ‘adventures’ in the historic house:



We were able to share our ideas and plans for Dementia Adventure and really listen to what people living with dementia (and their carers) want in terms of days out, short breaks and longer holidays in the UK and abroad.

Quotes from people who attended and made the events so special:

“It’s about exercise and
beauty isn’t it?”

Lady living with dementia

“Thanks for being brave
and taking this on”

Gentleman living with dementia

“Thank you for setting this
up, it is important for carers
and people with dementia
to be around others who
understand how they feel,
just offering opportunities
to get out of the house
means a lot to people”

Family carer

“It’s the brightest I’ve seen
my mother for a long time.”

Family carer

“The idea of a week’s holiday,
maybe here or abroad, is
something we could think
of in the next year.”

Family carer

9.3 Appendix C: Case study 2 – Dementia Adventure CIC

Dementia Adventure at Standen
National Trust March 26th 2010

Dementia Adventure teamed up with the people at Innovations in Dementia CIC to enjoy a day out at Standen National Trust in West Sussex. Innovations in Dementia’s “Think Tank” combined a consultation discussion with a day out at this Arts and Crafts property. Standen is hidden at the end of a quiet Sussex lane with breathtaking views over the High Weald and Weirwood reservoir. The design of the house is a monument to Philip Webb and William Morris. The gardens and house were enjoyed by the group on a fresh and breezy day with the first hints of spring in the air. People living with dementia enthused about the intricate and delicate artwork on display, with one gentleman living with dementia saying *“You know when we do these things I forget I’ve got dementia”*. The group shared in the joy that is Standen together, including a hearty lunch in the beamed barn. As part of the consultation we asked people living with dementia:

What makes a good day out?

“Getting out into nature.”

“Places where you feel safe.”

“Going as a group can make you
feel safer.”

“Having support from someone
you know well.”

How does dementia impact on getting out and about?

"I get bored of my local area. I like to get further a-field. But now I'm completely frightened of going alone."

"I need organising. But then I'm waiting for people to turn up."

"My family clamped down on me going away on holiday. It feels like you are in prison."

"I got the fear. When I go away from my local area, it's a panic, a blank."

"You need things to fill the time."

"I only go to London on Sundays. It's too busy to go on your own."

About the day out and the impact on dementia:

"When I walk around looking at these things, I forget I have dementia."

"When you are with interesting people, the Alzheimer's goes."

"It's a unique place very beautiful."

"I would visit other National Trust places because of today."

"It's been educational, interesting and helpful."

"It would be useful to have names on the trees and plants."

"When you get a diagnosis of dementia, you can't get your life back. But you can get a new life."

9.4 Appendix D: Case study 3 – Innovations in Dementia CIC

The Walking Group film by Innovations in Dementia April 2010

The following quotes and information has been extracted from the online film produced by Innovations in Dementia available here: http://myid.org.uk/videos_walkinggroup.htm

Does a diagnosis of dementia mean that life is over? Not according to the members of the Walking Group. The Walking Group is made up of members of the Forget-me-Not Centre in Swindon who walk across the Wiltshire countryside. Along the way we hear how members of the group are making the most of life with dementia, and why it pays to keep positive.

Quotes:

"Life doesn't just end because you got dementia."

"I still get down times, but I get up times, like this today [walking in the hills near Swindon] I'll be on top of the world when I get home."

"The way I've tried to get round it is going for walks...I've been to places I wouldn't have seen in a normal life."

"I'll get up and have breakfast and walk into Swindon, which'll be about an hour, go to the library and read the papers. One, I'm cutting my expenditure down, secondly I'm getting exercise."

"Don't be embarrassed by using a walking stick."

"Regardless of whether it's Parkinsons or whether it's Alzheimer's or whether it's one of the other, of the many, we need to pull everybody together like a united front."

"My life is positive. It wasn't when I first got diagnosed, but it is now."

"When you get diagnosed with dementia or Alzheimer's you wake up and look at it, it's another part of the adventure in life and you go on from there rather than hiding away."



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9.5 Appendix E: Quotes from 2000–2002

"Once upon a time I could remember all that happened to me. Now as I am older I find that I remember less and forget more. I have tried many ways of re-informing my memory but it seems to have little result. But I have found that when I am with others and we talk over our views or experiences my memory revives and it brings my thoughts to become more of a reality."

"My brain is going."

"I have got arthritis in my knees and in my head."

"It's like being in Jail, can't do this can't do that."

"I thought my mind was finished."

"My memory began to sink and has given me a lot of problems."

"Somebody has pulled the plug on my life."

"My memory is shocking and I know I won't be able to keep up with people and it's disappointing."

"I'm in a sea of desperation."

"It's like railway tracks, I am on the slow one and my wife is on the fast one."

"I'm constantly walking the tightrope, trying not to get things wrong."

"I'm in the deepest of holes."

"I've outlived my usefulness I should be six feet under."

"It drives me round the bend."

"My brain is shrinking."

"It's like entering a whole new world."

"I'm a lot slower."

"I'm finished, I am ready to go into a coffin."

"I'm going mad, there's some changes going on in me, I think I'll chuck myself in the river."

"I was the brainy one, it's melted now, it's melted my heart."

"My brain is slowing down"

"I feel like killing myself."

"You've got to take things steady."

"My brain has slipped."

"It's hidden somewhere, this illness, very frustrating."

"I am ageing quicker than I would like to."

9.6 Appendix F: Walking interview – semi-structured interview questions

Case study 1:

1. When do you feel your best or feel well?

2. How often do you go out walking in nature?

3. How long do you walk for on average each time?

4. How long have you been doing this type of walking (out in nature)?

5. Do you follow paths and marked routes or do you make your own route?

6. Do you use maps, mobile phone, walkie talkies or any other equipment or technology to help you on your walks?

7. Below is our importance scale about walking out in nature. Please score the following items to tell me how important each item is for you:

Scale:	1 is not very important 5 is very important				
	1	2	3	4	5
Scenery					
Wildlife					
Being part of a group					
Being on your own					
Exercise					
Fresh air					
Getting out of the house					
Independence					
Meeting people					
The seasons					

8. What else is important to you about walking in nature?

9. What do you particularly like about walking out here in this place? (sense of place, belonging, familiarity)

10. How does this experience, of walking out in nature, effect how you feel and about your quality of life?

11. If something stopped you walking out here, temporarily for example like an illness or injury, what effect would this have on you?

12. How does walking out here in nature influence your view of your dementia and your symptoms associated with the illness?

13. In government and policy the phrase "living well with dementia" is increasingly being used. What are your thoughts about what this means to you?

14. What advice would you give to someone who is considering organising or setting up their own nature walks for people living with dementia? (what would you list of "do's and dont's include" or What pitfalls did you encounter and how did you get past them?

ADDITIONAL COMMENTS:

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9.7 Appendix G: Experts on line survey questions and summary response data

1. I agree to take part in this research by completing this questionnaire

• Response Percent:	100.0%
• Response Count: Yes	28
• No:	0.0% 0
• Answered question:	28
• Skipped question:	0

2. Please briefly describe your role and how long you have been in your role

• ResponseCount:	28
• Answered question:	28
• Skipped question:	0

3. How strongly do you agree or disagree with the following statement: Human well-being depends on contact with nature

• Strongly agree:	42.9% (12)
• Agree:	39.3% (11)
• Neutral:	10.7% (3)
• Disagree:	7.1% (2)
• Strongly disagree:	0.0% (0)
• Rating Average:	1.82
• Response Count:	28
• Answered question:	28
• Skipped question:	0

4. How much contact do you normally have with nature and green space (for example going to the park, woods, countryside, etc.)? Your contact with nature and green space (please tick one)

ResponseCount:

• Every day	100.0% (8) 8
• More than three times a week but not every day	100.0% (9) 9
• Three times a week	100.0% (1) 1
• Twice a week	100.0% (6) 6
• Once a week	100.0% (2) 2
• Once a fortnight	100.0% (1) 1
• Once a month	0.0% (0) 0
• Once every two months	100.0% (1) 1
• Once every 6 months	0.0% (0) 0
• Once a year or less	0.0% (0) 0
• None	0.0% (0) 0
• Other (please specify)	1
• Answered question:	28
• Skipped question:	0

5. Green exercise is defined as: Engaging in physical activity whilst simultaneously being exposed to nature. How aware were you of the term “green exercise” before receiving this questionnaire?

Response Percent:

ResponseCount:

• Never heard of it:	35.7% 10
• Heard of it but not sure what it meant:	14.3% 4
• Heard of it and knew what it meant:	50.0% 14
• Answered question:	28
• Skipped question:	0



6. Recent research shows that green exercise is beneficial to mental well-being (for example improved self esteem and improved mood) for a wide variety of different people. How do you feel the benefits of green exercise will apply to people living with dementia?

- Green exercise will be more beneficial to people living with dementia: 32.1% 9
- Green exercise will be equally beneficial to people living with dementia: 60.7% 17
- Green exercise will be less beneficial to people living with dementia 0.0% 0
- Don't know 7.1% 2
- Answered question: 28
- Skipped question: 0

7. How strongly do you agree or disagree with the following statement: "As the progression of dementia advances there will need to be a proportionate increase in the support and facilitation on offer to enable all people living with dementia to benefit from green exercise"

- Strongly agree: 42.9% 12
- Agree: 42.9% 12
- Neutral: 10.7% 3
- Disagree: 3.6% 1
- Strongly disagree: 0.0% 0
- Answered question: 28
- Skipped question: 0

8. Which of the following groups might green exercise work best for? (please choose all that apply)

- Younger people living with dementia: 85.7% 24
- Older people living with dementia: 85.7% 24
- Physically fit/able people living with dementia: 89.3% 25
- People recently diagnosed with dementia: 71.4% 20
- People in the early stages of dementia: 67.9% 19
- People in the middle stages of dementia: 78.6% 22
- People in the advanced stages of dementia: 71.4% 20
- People with poor physical health: 67.9% 19
- People with dementia living in the community: 78.6% 22
- People with dementia living in residential/nursing care: 96.4% 27
- Other (please specify): 8
- Answered question: 28
- Skipped question: 0

9. Were your answers to the last question (question 8) based upon: (please tick one)

- Your own experience: 61.5% 16
- Your own research: 23.1% 6
- Anecdotal evidence: 0.0% 0
- Literature: 15.4% 4
- Other (please specify): 7
- Answered question: 26
- Skipped question: 2



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9.7 Appendix G: Experts on line survey questions and summary response data *continued*

10. How important are each of the following factors when considering who might benefit most from green exercise?

	Not important	Important	Very important	
• Age:	82.1% (23)	14.3% (4)	3.6% (1)	28
• Physical health:	42.9% (12)	53.6% (15)	3.6% (1)	28
• Stage of illness:	39.3% (11)	50.0% (14)	10.7% (3)	28
• Where a person lives:	32.1% (9)	57.1% (16)	10.7% (3)	28
• Answered question:	28			
• Skipped question:	0			

11. In your opinion what are the current gaps in research literature with regards to people with dementia and green exercise?

• Response Count:	28
• Answered question:	28
• Skipped question:	0

12. When thinking about what research is needed in the next five years what are your top three priorities?

• Response Count:	28
• Answered question:	28
• Skipped question:	0

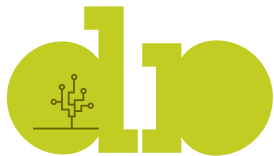
13. Would you like to be kept up to date with the results and outputs of this research?

• Yes:	89.3% 25
• No:	10.7% 3
• If yes, please supply a valid email address we can use to contact you in the future as we progress with the research	
• Answered question:	28
• Skipped question:	0



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