

Is it nice outside? - Consulting people living with dementia and their carers about engaging with the natural environment

First published 11 March 2016

Foreword

Natural England commission a range of reports from external contractors to provide evidence and advice to assist us in delivering our duties. The views in this report are those of the authors and do not necessarily represent those of Natural England.

Background

The Natural Environment White Paper “The Natural Choice: securing the value of nature” (Department for Environment, Food and Rural Affairs, 2011) sets out the need to strengthen the connection between people and nature. However, the White Paper also acknowledges that the opportunities to benefit from spending time in the natural environment are currently not open to everyone, which can contribute to health and other inequalities. Natural England is committed to increasing the number and range of people who can experience and benefit from access to the natural environment, and through the Outdoors for All Programme is leading the Government’s ambition that ‘everyone should have fair access to a good quality natural environment’.

The number of people with dementia is growing and is a costly challenge to society. Evidence, although fragmented and often qualitative, shows that engagement with the natural environment can have a positive effect on people living with dementia (Clarke et al, 2013) and these benefits can be grouped into following headings: improved emotional state: reduced stress, agitation, anger, apathy and depression; improved physical health: skin health, fitness, sleeping patterns, eating patterns; improved verbal expression; improved memory and attention; improved awareness: multi-sensory engagement and joy; improved sense of well-being, independence, self-esteem and control and improved social interaction and a sense of belonging. The National Institute for Health and Care Excellence (NICE) have issued new guidance based on the evidence relating to mid-life approaches to delay or prevent the onset of dementia, disability and frailty in later life and advocate a healthy lifestyle including being more active (NICE 2015).

The Greening Dementia report (Clark et al, 2013) also highlighted the potential barriers to engagement with the natural environment for people living with dementia. The report recommended large scale

research and evaluation studies to more robustly quantify the benefits of engaging with nature for people living with dementia, particularly with regard to the mental and physical health benefits and the cost benefits of different intervention types involving nature against more traditional medical treatments.

The Greening Dementia report acknowledged that people living with dementia need to be actively involved in helping to design projects and initiatives that seek to better enable them to benefit from access to the natural environment. Subsequent consultations with a range of dementia experts highlighted that for any intervention to be successful it was also critical to directly involve the people living with dementia and their family carers in any project design work. It recommended engaging more directly with people living with dementia because due to the complexity of the condition a ‘one size fits all’ approach was unlikely to be successful.

This study, ‘Is it nice outside?’, which follows on from the initial ‘Greening Dementia’ report, seeks to gather insights and information directly from people living with dementia and their carers. The findings from this collaborative project between Natural England, Dementia Adventure, Mental Health Foundation and Innovations in Dementia will be used to inform the design of a large-scale demonstration project that will deliver services in the natural environment for people living with dementia and their carers. For all enquiries about this future project please contact Dementia Adventure.

This report should be cited as:

MAPES, N., MILTON, S., NICHOLLS, V., WILLIAMSON, T. 2016. *Is it Nice Outside? - Consulting people living with dementia and carers about engaging with the natural environment*. Natural England Commissioned Reports, Number211. (The authors are listed alphabetically to reflect their joint lead authorship).



Mental Health
Foundation



Innovations
in Dementia

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Keywords - Dementia, carers, social evidence, social prescribing, diversity, public engagement, health care commissioning, social care commissioning, service integration, personalisation, health and wellbeing, outdoors for all, health, elderly, green care

Further information

This report can be downloaded from the Natural England website: www.gov.uk/government/organisations/natural-england. For information on Natural England publications contact the Natural England Enquiry Service on 0845 600 3078 or e-mail enquiries@naturalengland.org.uk

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ISBN 978-1-78354-302-1

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“What it is, the fact that if you are out in the open area, it brings a whole new perspective to how you feel, you are not in an enclosed space indoors where you are thinking well, this is my world, that’s their world out there. You go out into their world, as one might say, you enjoy walking, swimming whatever, anything which gives you more exercise to the body, actually exercises the mind as well and fresh air is excellent for people with dementia of any sort because mine should be getting worse all the time but it’s not. It is staying stable and as a result I am still walking, volunteer walk leader and I thoroughly enjoy it, I now walk about 60 miles a month on average.”

Participant - Canterbury

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Acknowledgements

The Mental Health Foundation and Innovations in Dementia and the authors would like to thank all of the people living with dementia and carers who took part in the project. Our thanks also go to staff who assisted with the consultations at the following locations:

- Forget Me-Not Group, Canterbury
- Healthy Living Club, Stockwell
- Homestead Park, York
- Laverstock Support Group, Salisbury
- Redditch and Bromsgrove Friends Together, Redditch
- Secret Garden Project, York
- West Berkshire Empowerment Group, Reading

Thanks also to:

- Members of the Project Steering Group:
 - Neil Mapes
 - Steve Milton
 - Sarah Preston
 - Toby Williamson
- Katrina Jenkins at the Mental Health Foundation who kick-started the carers' survey and was central to its development and dissemination, and Dr Paul Swift for assisting with completion of the report.

Executive summary

Background

Dementia directly affects around 800,000 people and a further 670,000 carers in the UK. Costs to the health service, local government and families are currently around £23 billion, and estimates suggest this may treble by 2040 (Prince et al, 2014). With an ageing population the number of people living with dementia in the UK is estimated to double in the next 30 years.

There is no cure for dementia and there are no universally accepted, effective treatments available. In many cases, unpaid family carers deliver the bulk of care, affecting their own physical and mental health. However, there are medications, services and methods of support that can help people with dementia to live well. Although in recent years there have been significant developments in government policy on dementia none are explicitly focused on outdoor activities and green spaces.

Spending time in the natural environment has been shown by many studies to have a beneficial effect on people's overall sense of wellbeing. Less research has been carried out about its effect on people living with dementia. The 'Greening Dementia' report (Clark et al, 2013) provides a helpful summary of the evidence. There has been little research about the benefits of and barriers to taking part in activities in the natural environment for people living with dementia that involves people living with dementia themselves.

This project aims to investigate what the key benefits are from engaging with the natural environment, for people living with dementia; what the barriers are to them doing this; and what changes could be brought in to make the natural environment more accessible for people living with dementia.

The objectives of the project were to obtain the views of 50-60 people living with dementia and 100-125 family carers in the following areas:

- levels of knowledge and awareness around the role of nature in helping people with dementia to live well;
- quantifying current levels of outdoor activity, or disengagement with activity post-diagnosis;
- identifying specific motivations/reason for engaging/not engaging with outdoor activity and nature;
- what would make local nature spaces more dementia-friendly for this group;
- identifying specific barriers and challenges for this group around staying active.

Methodology

The three methods used in this project were: a consultation with people living with dementia, an online survey of carers, and interviews with a small sample of carers. People with dementia were invited to take part via the Dementia Engagement & Empowerment Project network (DEEP). DEEP consists of over 50 independent 'involvement' groups across the UK

led by or actively involving people with dementia. Seven different groups from across England participated in the project. Recognising that consulting people living with dementia required more creative approaches this project was guided by the principles of co-production. 16 people living with dementia contributed to developing the framework that shaped consultations with support and empowerment groups. 50 people living with dementia took part in 8 focus groups and an additional 4 were interviewed face to face.

Links inviting people to the online survey for carers were disseminated via the Mental Health Foundation's regular e-bulletin (over 55,000 supporters) and via Twitter and Facebook (over 100,000 followers). It was tweeted by a national carers' organisation and an item was included in the National Dementia Action Alliance's e-newsletter (over 3,200 member organisations). 172 carers completed the on-line questionnaire plus 10 were interviewed by phone. Although participants were self-selecting the numbers were large enough and the methodology robust enough to expect a reasonable range in terms of demography and experience.

We believe this to be the largest project to date that has collected evidence from both people with dementia and carers about engagement with the outdoors and nature.

Key findings

The three methods of consultation: focus groups with people living with dementia, an online survey of carers, and interviews with a small sample of carers, led to the following key findings:

Context

Generic Findings

There were three findings that provide important context for this work:

- Where people with dementia go (or want to go) and what they do there (or want to do there) is heavily influenced by where they live (e.g. city or countryside) and their conceptualisations of nature. The majority of people with dementia who participated lived in urban areas. Public parks and gardens were popular places to visit, but the countryside mentioned much less often. However, over 50% of carers who participated lived a mile or less from farmland or countryside and for these people the countryside was reported as being a popular place to visit. For people with dementia their concept of the natural environment was also an important factor in influencing their preferred visiting locations. For example, outdoor spaces with water were very popular visiting destinations. For people with dementia, their concept of the natural environment may be influenced by a number of factors including present day experience, memory, emotional and idealised views of nature. Knowing how much these factors are influenced by dementia was beyond the scope of this project and there is merit in giving further consideration to how far the views of people with dementia differ from those who do not have the condition.
- Only 20% of the people living with dementia cited their dementia as a barrier to using outdoor spaces, whereas 83% of carers believed that dementia limited the person's ability to use outdoor spaces.

- Over half of the carers (55%) said that the person living with dementia had other health conditions or a physical disability that limited their use of outdoors spaces and nature – this correlates with evidence from elsewhere about co-morbidities and dementia.

Findings from both people living with dementia and carers

The findings below apply to both people living with dementia and their carers. Separate findings from the two groups are described in the main body of the report.

Activities

- Informal walking was the most commonly cited activity by people living with dementia and carers. Informal walking was mentioned by 38% of people with dementia and 33% of carers, as something the person they cared for did at least several times a week. What walking meant to the person living with dementia came up strongly during interviews with carers, several of whom talked about the calming effect that this had on the person they cared for. This was vitally important to some as an escape from the pressures of being indoors, and could be as important to the carer as to the person with dementia.
- Wildlife watching, usually bird watching, is very popular amongst people living with dementia. In the survey 25% of people were said to take part in it several times a week or every day. 25% of people living with dementia had an interest in encounters with wildlife, one specifically with birds of prey. In the interviews with carers, six of the ten people interviewed talked about the person they cared for enjoying spending time watching – and sometimes listening to birds.

Places

- Places associated with water (inland, coast, natural, artificial) were the most popular places to visit for people with dementia (45%) and in the carers' survey over 25% of people living with dementia visited rivers, canals and waterways, or seaside, beach and coastal areas, at least once a month. (It should be noted that people living with dementia were asked about places they liked to visit, whereas carers were asked to state the frequency with which the person they cared for visited such places).
- In interviews with carers, several interviewees talked about the person they cared for enjoying time by water. Lakes in particular were places that were talked about positively as being environments where the person living with dementia and their carer could relax. For others, however, proximity to water could instill fear due to bad memories. Thus the picture that emerged overall from carers was far less positive than that coming from people living with dementia.
- City parks or public gardens were also places that were very popular to visit among people with dementia. About 30% of people with dementia talked about visiting city parks and gardens. 46% of carers said the person with dementia visited one or the other at least once a month with almost two thirds (63%) living less than one mile away from a park or public garden. Several people with dementia talked passionately about the role their local park played in providing them with somewhere to go, and as somewhere to enjoy watching other people taking part in activities.

Key factors helping or hindering engagement with nature

- Transport and mobility were the most important factors for both people with dementia and carers; availability, 'someone to take me', or personal attributes (limited physical mobility).

Recommendations

The consultation generated a good deal of information about how people living with dementia in their own homes, interact with nature and the activities that they engage in.

Comment

Many local outdoor spaces are underused by people with dementia. The reasons for this were not always clear, although factors such as perceived danger were highlighted, but a simple lack of awareness and information about what those spaces have to offer may have contributed as well.

Recommendation 1: Local directories of dementia-friendly open spaces and facilities should be developed by local dementia action alliances, perhaps using a 'trip-advisor' approach or by conducting an audit, to encourage greater use of natural spaces by people living with dementia. Managers of natural environments and organisations providing activities in outdoor spaces should be encouraged to develop and follow the principles of dementia-friendly communities.

Comment

The findings of the consultation suggest strongly that activities are the main motivating factor for engaging people with dementia with the natural environment. The project found that people living with dementia were motivated to take part in social activities such as guided walks and listening to the birds and music in outdoors spaces, and enjoyed informal walking as an activity in itself and as a means of calming down and relaxing, but also slightly more ambitious activities such as community gardening or farming.

Recommendation 2: Organisations planning or providing activities for people living with dementia need to take account of the importance of social activities as a key factor in stimulating engagement. Local services responsible for outdoor public spaces should consult with relevant groups and individuals with dementia (through local DAAs, where they exist) to gain an understanding of how best to ensure the inclusion of people with dementia in the activities they provide.

Comment

However, place was also important and clear views were expressed about the preference for people living with dementia and carers visiting locations with access to water (inland, coast, natural or artificial), closely followed by public parks and gardens. The strength of this association appears to combine an emotional concept of nature (positive, soothing, aesthetic qualities associated with water) with the practical reality of many people's day to day engagement with nature which may be limited by geographical location or factors such as transportation, support, physical mobility, or the impact of dementia.

Recommendation 3: Organisations planning and providing activities for people living with dementia should take into account the type of place that motivates people living with dementia to be engaged.

Comment

Significant barriers to participation by people living with dementia were a lack of transport and inadequate support both to get to locations, to use facilities and to participate in outdoor activities.

Recommendation 4: Collaborative working between organisations providing services to people with dementia, organisations managing outdoor spaces, local transport organisations and through local dementia action alliances, for example, could generate innovative partnerships and solutions to enable people with dementia to access public spaces outdoors.

Comment

Linking this activity with the movement towards ‘dementia friendly communities’, and the work of local DAAs, increases the potential for positive engagement, impact and sustainability. All of these could significantly enhance the potential for people living with dementia to feel part of the community and to enjoy their local nature spaces.

Carers tend to be more cautious than people with dementia about what the latter can do outdoors and have concerns about issues such as safety when in natural environments.

Recommendation 5: Carers’ organisations and the providers of support to people with dementia have a role to play in encouraging family carers and paid staff to be more ambitious in their expectations of what people with dementia can do. This could be achieved through the sharing of innovative good practice highlighting the positive outcomes, and how concerns and practical difficulties have been overcome to enable someone living with dementia to participate in outdoor activities safely.

Comment

The findings of the consultation allied to previous research evidence indicates that people with dementia often suffer multiple disadvantages in accessing and using structured environments such as parks. Problems with mobility, tiredness and disorientation can have a significant impact on the ability of people living with dementia to enjoy them. In particular, the availability of accessible signage, toilets and cafes, places to sit and relax located in spots with even ground that are easy to find, and the presence of someone trained in dementia awareness to offer support and information.

Recommendation 6: Organisations designing and managing outdoor spaces should ensure the availability of accessible signage, facilities such toilets, cafes, places to sit and relax which are easy to find, walkways located on even ground, and the presence of someone trained in dementia awareness to offer support and information.

Recommendation 7: Greenspace managers should fulfil their obligations under equalities legislation to make reasonable adjustments and to consider the specific needs of people with dementia. They should form local alliances with groups and individuals with experience

of dementia, or join existing ones (such as local dementia action alliances) to assist in planning, training and quality assurance in the delivery of services.

Comments – Recommendations 6 and 7

Some providers of managed outdoor environments may already be working towards this and some may be aspiring to make these changes but don't know how to implement them.

Undertaking dementia-accessible audits involving people with dementia, providing 'dementia friends' awareness sessions, offering more specialist training and becoming part of a local dementia action alliance (where one exists) are some of the ways in which these change processes can be put into effect.

1. Introduction

Background

1.1 Dementia is an umbrella term for a range of conditions that cause damage to the brain. This damage can impact on a person's memory, thinking, language and their ability to carry out everyday tasks. There are many conditions that cause dementia. Alzheimer's disease is the most common, but there are many others, including vascular dementia, Lewy body dementia and fronto-temporal dementia. Dementia is a progressive illness with damage to the brain and associated symptoms that gradually get worse over a period of time. Dementia is often described as early onset, middle stage and late stage dementia, or mild, moderate and severe, though some symptoms may occur earlier or later in individuals and there are no clear cut offs between these various stages. Each person's experience with dementia is unique.

1.2 There are over 800,000 people with dementia and 670,000 family members or friends acting as carers of people with dementia in the UK. The risk of developing dementia increases with age; it affects one in 14 people over the age of 65, but one in six people aged over 80. As an 'ageing society' with more people living longer, it is estimated that there will be over a million people in the UK living with dementia by 2025. Whilst dementia is an age-related set of diseases there are an increasing number of younger people being diagnosed with dementia. Two thirds of people with dementia live in their own homes and one third, usually those with more severe or advanced dementia, live in care homes. Dementia costs the UK approximately £26.3 billion per year in terms of costs of health and social care, unpaid care, etc. (Prince et al 2014).

1.3 In 2009 a five year national dementia strategy for England was published by the Department of Health (Department of Health 2009). This focused on improving awareness, diagnosis rates, post-diagnostic care and support, support for carers and research into potential cures or disease modifying treatments. In 2012 the Department of Health published the Prime Minister's 'Challenge' on dementia (Department of Health 2012). This included a commitment to developing 'dementia friendly communities' whereby any organisation that might have contact with people with dementia (including those responsible for green spaces) should consider how it could be more inclusive and supportive of people with dementia. Much of this work has been supported by partnerships formed by local organisations, known as 'Dementia Action Alliances'. In 2015 the challenge was updated with additional emphasis placed on risk reduction and prevention, including acknowledgment of the benefits of physical exercise and activity (Department of Health 2015). In addition to these policy initiatives the National Institute for Health and Care Excellence (NICE) have issued new guidance based on the evidence relating to mid-life approaches to delay or prevent the onset of dementia, disability and frailty in later life and advocate a healthy lifestyle including being more active (NICE 2015). However none of these policies have contained an explicit focus on outdoor activities and green spaces.

1.4 Access to the natural environment benefits people's mental and physical health and sense of wellbeing and contributes to their quality of life. The case for this is now well-

established and there is a substantial body of credible evidence in this area (Clarke et al. 2013). There is also a body of evidence examining the link between improved human health and exposure to 'nature' in urban settings, including research into the benefits of community gardening and allotments, which points to a range of benefits including improving people's quality of life, reducing exclusion and helping people to relax (Ferres and Townshend University of Newcastle 2012). While none of this research was specifically about people living with dementia, its findings include outcomes that are of enormous relevance to people living with dementia.

1.5 In 2012 Natural England published 'Greening Dementia', a review of the existing evidence of the benefits and barriers facing people living with dementia in accessing the natural environment and their local green space. This review drew on published and/or peer reviewed literature by accredited academics and researchers plus a range of grey material held in reports or unpublished project reviews and evaluations, as well as findings from a qualitative stakeholder consultation. The consultation included stakeholders from a variety of greenspace, dementia-specific and health and social care organisations.

1.6 The review found that evidence of benefits for people living with dementia from access to the natural environment is limited and often qualitative. However, general findings can be grouped into:

- Improved emotional state: reduced stress, agitation, anger, apathy and depression
- Improved physical health: skin health, fitness, sleeping patterns, eating patterns
- Improved verbal expression
- Improved memory and attention
- Improved awareness: multi-sensory engagement and joy
- Improved sense of well-being, independence, self-esteem and control
- Improved social interaction and a sense of belonging.

1.7 The review also found that evidence of the benefits of access to specific types of natural environment (i.e. woodlands, coastal, mountains) and the effect of specific activities on people living with dementia, was generally poor. On-going studies within care home settings suggested that a variety of interventions such as developing dementia friendly garden spaces and facilitating organised park and woodland walks could have positive benefits for people living with dementia. However, as approximately two-thirds of people living with dementia currently live in their own homes and tend to be at the earlier end of the onset of dementia, the review pointed out that it could be argued the interaction of this group with nature should be the focus of any future intervention.

1.8 Another finding from this review was that there was limited evidence focusing on specific barriers facing people living with dementia in accessing the natural environment, though these findings were supported by studies looking at the barriers for people more generally. The evidence reviewed showed that barriers particularly affecting people living with dementia include: concerns about how they will be perceived; a lack of awareness of the needs of people living with dementia among greenspace organisations and their staff; the costs of resourcing visits, including transport and carer costs; and the impact of risk aversion among people living with dementia, their carers and service providers.

1.9 'Greening Dementia' found eight studies that directly involved people living with dementia, and one of its key recommendations was that future research work should be user-led and actively involve people living with dementia in helping to shape future projects. In recognition that traditional consultation processes are not appropriate for many people living with dementia, especially as onset progresses, it urged that creative approaches including walking interviews and participatory appraisal approaches be explored.

1.10 This study was informed by these recommendations. It sought to involve people living with dementia in a co-production process to gather their views and to gather the views of family and personal carers about the role of the natural environment in helping people with dementia to live well. It was commissioned by Natural England and developed as a partnership project between Dementia Adventure, Natural England, and the project delivery partners the Mental Health Foundation and Innovations in Dementia.

1.11 It was a nine month project that was completed in 2015.

Aims and objectives

1.12 The aim of this project was to gather the views of people living with dementia and carers about the role of outdoor activity and natural outdoor spaces in helping people with dementia to live well.

1.13 The objectives of the project were to obtain the views of 50-60 people living with dementia and 100-125 family carers in the following areas:

- Levels of knowledge and awareness around the role of nature in helping people with dementia to live well;
- Quantifying current levels of outdoor activity, or disengagement with activity post-diagnosis;
- Identifying specific motivations/reason for engaging/not engaging with outdoor activity and nature;
- What would make local nature spaces more dementia-friendly for this group;
- Identifying specific barriers and challenges for this group around staying active.

Methodology

1.14 The information gathering was carried out through a mixed-methods approach in partnership with the Mental Health Foundation and Innovations in Dementia. The Mental Health Foundation was responsible for gathering the views of carers of people with dementia and Innovations in Dementia were responsible for collecting the views of people with dementia. Different approaches were taken in gathering information from people with dementia and carers in recognition of the difficulties that some people with dementia may have with more conventional survey methods; the differences are described in more detail below.

1.15 The Mental Health Foundation is a UK charity that undertakes social research, service development and policy work on issues affecting people with mental health problems, dementia, and learning disabilities.

1.16 Innovations in Dementia is a community interest company that works nationally with people with dementia, partner organisations and professionals. Its aim is to develop and test projects that will enhance the lives of people with dementia.

1.17 The aim was to ensure that the numbers of participants was large enough, given the time and resources available for the project, to potentially generate meaningful findings in quantitative terms, as well as qualitatively. However it should be noted that this was a consultation rather than a more formal research project and the findings should be read with that in mind.

People living with dementia

1.18 People living with dementia were involved in a co-production process to develop the consultation framework so that the views of people with dementia would be heard clearly and most effectively. A co-production approach aims to include people who are the focus of a service development or piece of research as equal partners. In this context there are particular sensitivities around communicating with people living with dementia, some of whom may be easily confused or find it difficult to stay with one topic of conversation; some of whom find it hard to be in a group or to express themselves in a group; some of whom cannot communicate verbally at all. For this project, 14 people with dementia were consulted and the researcher worked together to test out questions and concepts for the focus groups. The project aimed to involve 50 people living with dementia. In total, 54 people were involved, 50 via focus groups and 4 via one-to-one interviews.

1.19 A series of focus groups were set up around England, as well as one-to-one conversations by telephone with people with dementia who were either not part of a group or who preferred another way to feed into the process. The groups consisted of people with various forms of dementia, with an age range from 50 years of age to people in their late 80's. Some had early-stage dementia, while others had more advanced dementia and received more support to have their voice heard.

1.20 Focus groups were recruited through the Dementia Engagement and Empowerment Project (DEEP)¹. Eight focus groups were held in March and April 2015 in the following locations:

- Stockwell - The Healthy Living Club - Group 1 (12 people with dementia)
- Stockwell - The Healthy Living Club - Group 2 (6 people with dementia)
- Redditch - Redditch and Bromsgrove Friends Together (8 people with dementia)
- Reading - West Berkshire Empowerment Group (5 people with dementia)
- Canterbury - The Forget Me-Not Group (9 people with dementia)
- Salisbury - The Laverstock Support Group (5 people with dementia)
- York - The Secret Garden Project (3 people with dementia)
- York - Homestead Park (2 people with dementia)

¹ <http://www.dementiavoices.org.uk>

1.21 One-to-one interviewees with people with dementia were invited through the DEEP network: four such interviews were conducted with people with dementia not involved with the focus groups.

1.22 All participants were able to give their consent to participate in discussions. In order to ensure a relaxed and informal feel to the focus groups demographic information was not collected but the facilitator noted that overall the numbers of men and women participating was fairly even and the majority of people were white British.

What the research asked about

1.23 At the outset of the project some key research questions were identified to explore with people with dementia.

- How do people engage with outdoor green space?
- Has people's use of outdoor space changed since getting their diagnosis of dementia?
- What helps them to connect with outdoor green space?
- What gets in the way?
- What could be done to help them make better use of outdoor green space?
- What would they like to do in green space given the right support?

1.24 These questions were re-formulated into areas that were easier for people living with dementia to follow, as a result of which data was gathered in six main areas:

- Where do you go?
- What do you do there?
- What is good? What helps?
- What is bad? What gets in the way?
- What would you like to do?
- What do you need to make that happen?

1.25 Initial work with people with dementia identified the need to adopt a flexible approach. In practice the conversations with the focus groups necessitated an even more flexible approach than we had anticipated, principally because:

- All of the groups we worked with were existing groups and in most cases people knew each other well - so there was often a good level of chat or 'banter' and deviation into other conversation areas, which required sensitive facilitation to keep the discussion on track.
- Many of the groups were quite mixed in terms of the ability to engage - with some needing a lot more prompting and encouragement than others - and a more rigid approach would have risked individuals disengaging with the consultation.

1.26 However, this approach has resulted in a rich data set - enabling us to ground our findings in the perspectives and priorities of participants - rather than existing preconceptions.

1.27 Most of the groups were facilitated by one person (Innovations in Dementia lead), except for the York groups and the Salisbury group, which were facilitated by two associates of Innovations in Dementia. Headline findings and audio files were passed onto the lead. All of the Innovation in Dementia lead's group sessions were audio taped, as were two of the one to one interviews.

1.28 The focus groups all took place in the usual meeting space for each group - experience shows that this works best for most people - rather than in more formal and unfamiliar settings. One of the impacts of this was that in some cases 'membership' of the discussions was fluid, as some of the group's activities were going on elsewhere.

1.29 The sessions were delivered as 'guided conversations' with a loose topic structure - the main aim being to get people talking about "outdoor green space" - and once that was established to then lead into talking about what helps, what gets in the way, and what people would like to do.

Carers

1.30 In order to collect the views of carers, the Mental Health Foundation first undertook an online survey which ran for three months from January 2015 until the end of March 2015. The survey was designed in consultation with the project steering group and specialist dementia organisations, and piloted with 12 individual carers (see Appendix A). The final version included 24 questions aimed at finding out why people with dementia do or don't participate in outdoor activities and nature, as well as how to make nature spaces more dementia-friendly. Most of the questions were closed (yes/no; either/or type questions) or used rating scales to find out about people's frequency of use of outdoor spaces and related information. There were also three open questions where respondents could give their views on: how the dementia had affected the person's ability to use nature spaces; what support and information would enable the person living with dementia to participate in various activities; adaptations they would suggest for making nature spaces more dementia-friendly; and one open question for further comments.

1.31 An invitation to complete the questionnaire was sent out to a variety of national networks including:

- The Mental Health Foundation's supporters' e-bulletin (49,000 subscribers);
- Natural England and Dementia Adventure's networks
- Carers' Trust supporters
- The Dementia Engagement and Empowerment Project network (DEEP), a national network of groups actively involving or led by people living with dementia.

1.32 The questionnaire was available to complete during March 2015. There were 172 respondents (target = 125). Not everybody answered every question, and the findings are based on the numbers replying to each question.

1.33 When replying to the survey, some questions asked for the respondent's own views/experiences, while some questions asked the respondent to answer on behalf of the person with dementia being cared for.

1.34 Ten telephone interviews were subsequently carried out with carers of people living with dementia, in order to follow up the themes that had been identified during the survey. The interviews followed a topic guide (see Appendix B) and were recorded. The recordings were transcribed and analysed according to the key themes identified in section 1.2 above.

1.35 Interviewees were recruited from the Foundation's older people's virtual panel and, via members of this panel, carers involved in local support groups across the UK. All had experience of being a personal or family carer for someone with dementia: some also had experience in roles as professional carers. This meant that, while the interviews were mainly structured around questions aiming to elicit information about individuals known by the interviewee, sometimes interviewees talked about people in care homes or other care settings. The main focus for the interviews was, however, carers' views about the relationship that the person with dementia who they cared for, or had cared for in a personal or family capacity, had with the natural environment.

1.36 The topic guide for the interviews was drawn from the original aims of the project and from themes brought up by either carers of people with dementia in the carers' survey, and the consultation with people with dementia. In particular it aimed to find out about:

- The role of the natural environment in helping people with dementia to live well;
- How people with dementia engaged in nature or outdoor activities;
- What they enjoyed about this; and
- What were the main barriers to them taking part in or enjoying outdoor spaces.

1.37 People were also asked about particular activities that had been identified in either the survey or consultation as being popular with or important to some people with dementia.

Robustness and limitations of findings

1.38 All participants were self-selecting and gave their consent to be involved in the project. This meant that it was not possible to guarantee that the participants were representative of people with dementia or carers in terms of demographic profile or experience. People with (usually more severe) dementia who would be unable to give their consent to participating in the project were not included. However, the target number of participants was successfully achieved and in the case of the online survey, exceeded. It is therefore believed that the numbers were large enough and the methodology robust enough to expect a reasonable range in terms of demography and experience and that the findings have sufficient weight to support the conclusions and recommendations. It is also believed that this is the largest single project to date that has collected evidence from both people with dementia and carers about engagement with the outdoors and nature.

Definitions

1.39 For the purposes of this report the natural environment is defined as including different types of green space such as allotments, urban and country parks, wilderness areas, open countryside, woodlands, waterways and canals and wildlife reserves. In the report the terms 'outdoor activity' and 'nature' are also used to describe outside spaces with

which people with dementia might engage. The carers' survey defined 'nature' in the following way:

Nature refers to any public space within a natural environment including:

- Parks and public gardens
- Community allotments and city/urban farms
- Cemeteries and churchyards
- Woodlands, forests and national parks
- Rivers, canals and waterways
- Farmland and countryside
- Moorlands and mountains
- Seaside, beach and coastal areas

1.40 In this survey, nature does not include private/home gardens. The same terminology was used for the interviews with carers: for the interviews, however, private or home gardens were not excluded. Given that the responses from the survey indicated that people with dementia were most likely to take part in activities near to where they lived, interviewees were asked about outdoor spaces near to where the person with dementia lived, and this led to people talking mainly about gardens or parks. The term 'living with dementia' is used to mean someone who has diagnosed with a type of dementia.

Nature refers to any public space within a natural environment including:

- Parks and public gardens
- Community allotments and city/urban farms
- Cemeteries and churchyards
- Woodlands, forests and national parks
- Rivers, canals and waterways
- Farmland and countryside
- Moorlands and mountains
- Seaside, beach and coastal areas

2. Findings from people living with dementia

2.1 From the conversations in the focus groups with people living with dementia key themes and sub-themes were identified from an initial reading of the transcribed audio. Individual occurrences of each theme were then identified - discounting multiple references by single participants, and refining categories in the process.

2.2 In this section 'n' ('number') refers to the number of individuals who mentioned the relevant theme. Multiple references to a theme by the same individual participant have been discounted.

2.3 There was some crossover between the areas explored but for the purposes of clarity and brevity this section is grouped into four main areas:

- Where do people with dementia go?
- What do people with dementia do there?
- Factors preventing or promoting engagement
- What would people with dementia like to do and what would help make that happen?

Where do people with dementia go?

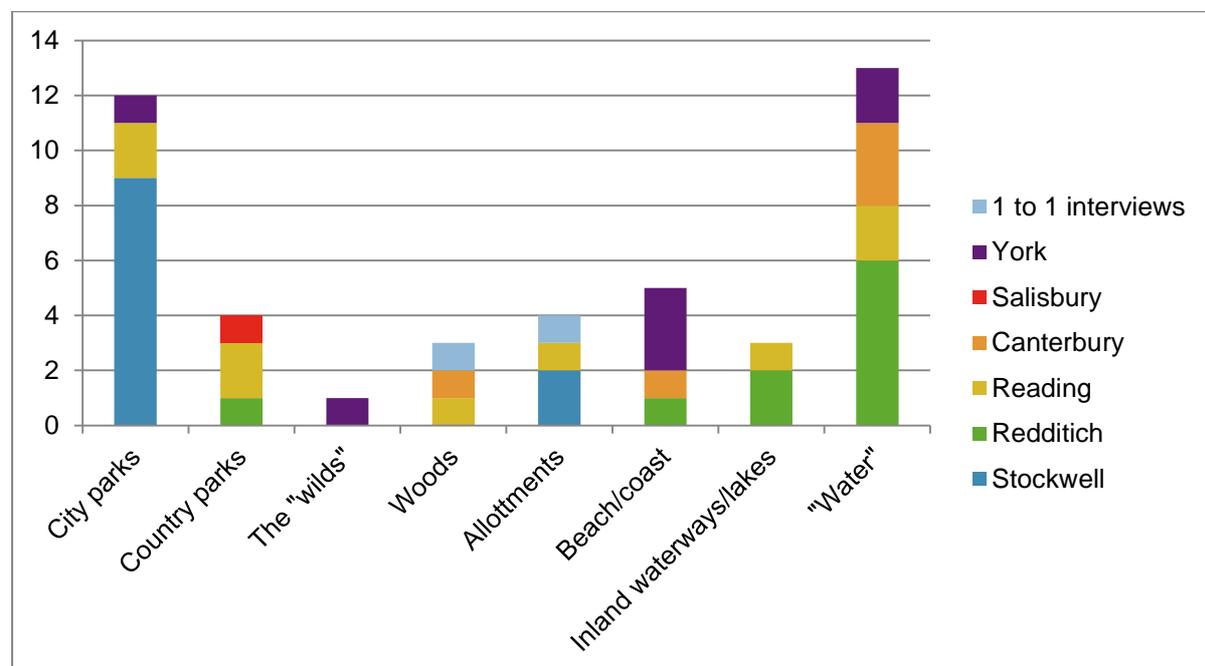


Figure 1 Where do people with dementia go?

2.4 As can be seen from Figure 1, spaces involving water (29%) and city parks (27%) were the most frequently mentioned environments. A striking feature of the data was the number of references to water. If all references to the water theme are taken together, 45%

of people living with dementia who took part in the consultation, referred to places involving water. Some participants made clear expressions about the appeal of water, as illustrated by the following quote:

"I say what would attract me more than anything, water. If we are going along and we see a lake, and we say oh let's go and have a look at that, and as I say it is the same about the seaside or something like that. I think water attracts me more than anything, whether it is a lake or a pool, or weir. You know you are near the coast and you park the car, I think water turns me on more than any other than just grass."

Participant - Redditch

People in Redditch also made good use of the many inland waterways for informal walking.

2.5 It is also clear from the figure that managed environments (city or country parks, allotments, inland waterways and lakes) feature much more significantly than more natural settings (woods, 'the wilds', beach or coast), with 45% of people mentioning managed environments, and only eight people (14%) mentioning more natural settings. The distinction between managed and natural settings makes sense for this study, partly because of the mainly urban location of the groups, and partly because there are important distinctions between the two in terms of how they are experienced. Managed environments are more structured and likely to include features that make people feel more secure such as paths, signs, and places for refreshments. Natural settings may include all, some, or none of these. They are more strongly associated with places that instill a sense of adventure.

2.6 City parks and allotments are particularly important to those living in Stockwell (inner London), and those in and around Reading. All councils, with the exception of inner London authorities, but including parish and town councils, have a duty to provide allotments (Barclay 2012), whose main purpose is to provide small plots of land where people can grow their own fruit, vegetables and flowers. 37% of references to different types of outdoor space were to one of these spaces;

"...that is how I first got into my allotment because I had just had my diagnosis about dementia and my doctor said don't let it get you down, keep going out and doing what you can, on the way home I saw a sign outside the allotments, open day, come and have a look and I went in there and he said how much do you want, I love it, I love being out and doing things and it does me the world of good to know that the stuff I am putting on the plate is what I have grown myself".

Participant - Reading

2.7 One striking feature of the conversations was the lack of interest in the past, with only two participants interested in discussing where they used to go in the past. This of course runs counter to a popular conception that people with dementia spend a lot of time living 'in the past', the prevalence of 'reminiscence' in activity schedules within health and social care settings for people with dementia being one manifestation of this. However, people were predominantly preoccupied with the present - what they do now, together with the future - what they would like to do.

What do people with dementia do there?

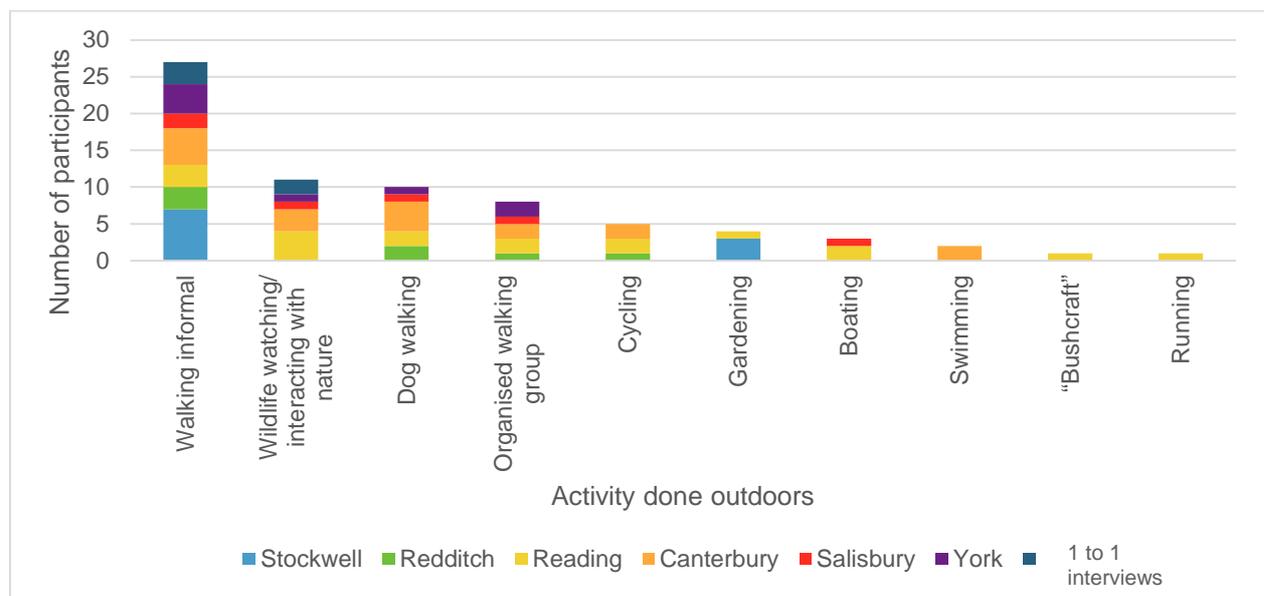


Figure 2 What people with dementia do outdoors

2.8 There was considerable crossover during conversation between ‘where’ people go, and what they do when they are there. Generally speaking, people were more interested in talking about what they did, (n=72) than where they did it (n=44).

2.9 By a significant margin, informal walking was the most commonly cited activity (37.5%). It was most commonly mentioned as an activity in itself, but also as a means of getting to or engaging in other activities.

“I think you have got to be a loner really, if you want to, because like with me, in Droitwich, the canal, and that canal goes all over the place. As I said I walk there, well I walk miles and miles and I come across a pub, and we go there sometimes now.”

Participant - Redditch

2.10 Organised walking groups were an important activity for eight participants, with one being a volunteer walk leader for a local (non-dementia) walking group:

“What it is, the fact that if you are out in the open area, it brings a whole new perspective to how you feel, you are not in an enclosed space indoors where you are thinking well, this is my world, that’s their world out there. You go out into their world, as one might say, you enjoy walking, swimming whatever, anything which gives you more exercise to the body, actually exercises the mind as well and fresh air is excellent for people with dementia of any sort because mine should be getting worse all the time but it’s not. It is staying stable and as a result I am still walking, volunteer walk leader and I thoroughly enjoy it, I now walk about 60 miles a month on average.”

Participant - Canterbury

Generally the experience of walking groups has been positive - though one participant had strong opinions on areas that could be improved (see next section).

2.11 An interest in wildlife or 'interaction' with nature was frequently given as the reason for exploring the outdoors, with references to both managed encounters (in one case, birds of prey) and less structured contact, including for one participant, hunting (though his gun licence has now been revoked).

2.12 Dogs and dog-walking were mentioned ten times across the groups, except Stockwell. People spoke of dogs as both a motivator to get exercise - but also as enjoyable company:

"Some little while ago, somebody tweeted and say that 'dog' is 'God' spelt backwards because he cannot be here himself he invented dogs so that they could help people like he is supposed to [laughter]"

Participant - Canterbury

Others mentioned a range of activities - cycling, swimming, running, boating, gardening. There was one mention of "bushcraft" (as defined in the quote below) which merits including as it highlights the benefits of encouraging volunteering, and a sense of a continuing contribution by people with dementia:

"Well we made a little, umm, den. Likes of us old codgers as it were, but older people getting out and about and building something in the community, well it was down by the nature discovery centre, there was a little area, we built a little den, that was a covered in thing, for the benefit of the youngsters. I think sometimes there is issues whereby youngsters don't trust the older people and sometimes there is issues where older people think all the youngsters are up to no good, but I am sure there has got to be a major percentage of people that are by and large good and the few bad 'uns spoil it for the rest."

Participant - Reading

2.13 There were a small, but significant number of comments about choosing to do nothing "outdoors" - not through inability, but as a matter of choice:

"I have to say if you are with a dog then I can see a reason for going out for the walk, but I am not, I certainly couldn't come up, I wouldn't mind a stroll but you know if I had a choice I probably would do something else really."

Participant - Kent

"Never been interested really – I'm a city girl at heart - now if we were talking shopping....."

Interviewee

Conversely, others had a much greater interest in being outdoors - and in exercise more generally:

"I do gym for an hour down me shed, lifting weights, 40lb weights and then I walk me dog...for an hour, minimum an hour in the country, across brown fields and all that, cycling I am out for at least an hour and a quarter in the

afternoon and I go to the gym three times a week on top of that. I have to do it because I feel really good.”

Participant - Canterbury

Factors preventing or promoting engagement

2.14 This section pulls together data arising from questions about barriers to engagement, as well as those factors which enhance and facilitate it. It also includes data about what would help as well as what does help, as sometimes it was difficult to disentangle these two perspectives.

2.15 The key factors in determining people's accessibility to and engagement with outdoor activity fall into four main areas:

- Facilities (n=76)
- The support of others (n=50)
- Personal attributes/feelings (n=40)
- Activities (n=32)

2.16 In this survey people cite the facilities themselves and support from others as the most significant factors in determining their level of engagement with the great outdoors. However, a similar question posed to people with dementia about engagement in their local communities in 2011 resulted in people overwhelmingly citing their dementia as the reason for their lack of engagement - rather than the availability or type of facilities on offer (Innovations in Dementia 2011). This is potentially very significant as evidence of a shift of perception on the part of people with dementia, away from a more biomedical model where their dementia is seen as the cause of their exclusion, towards what is known as a 'social model of disability' which considers other factors such as the accessibility of the environment, and the attitudes and behaviour of others towards the impairments caused by dementia as excluding people (Mental Health Foundation 2015).

Facilities

2.17 'Facilities' were the strongest determining factor for participants preventing or promoting their engagement with nature (28% of references) and could be broken down into a number of elements, as shown in Figure 3.

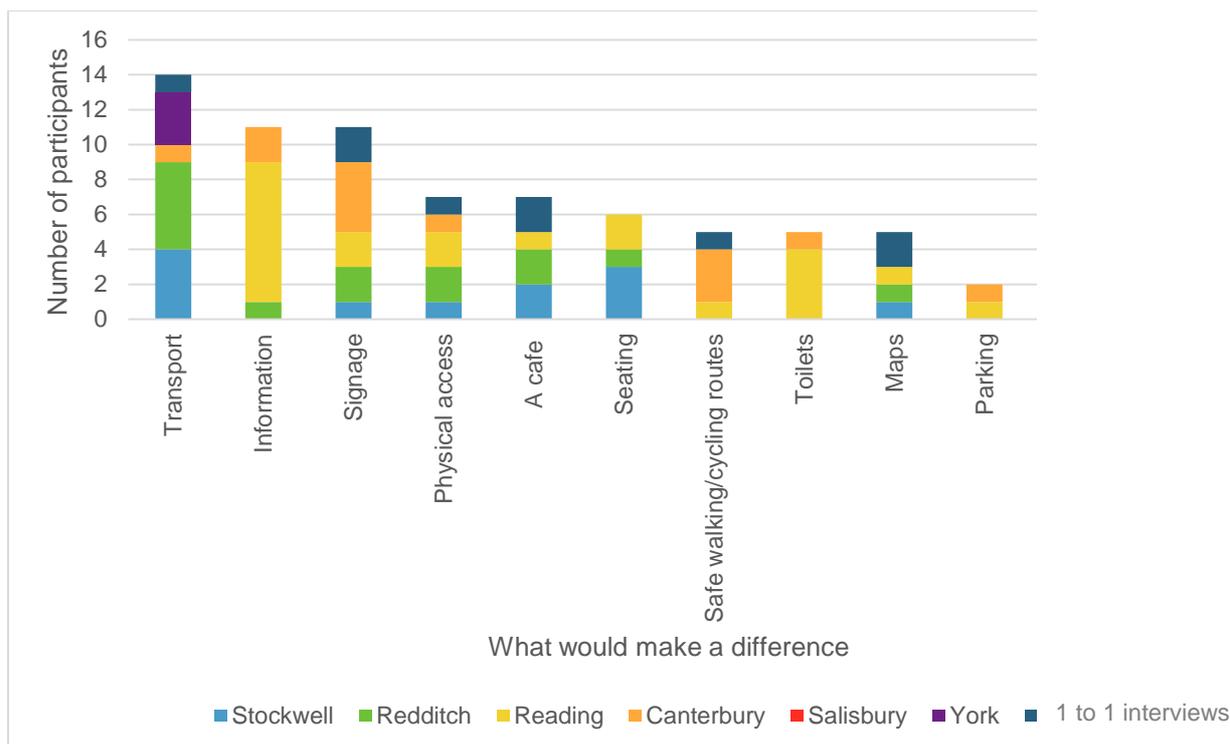


Figure 3 What facilities make, or would make a difference to outdoor spaces for people with dementia?

2.18 There were five main themes that emerged:

- Transport
- Signage, navigation and orientation
- Information
- Refreshments
- Physical access

2.19 **Transport** was the most frequently cited factor in either hindering or enabling access (18% of references) to help people to make greater use of outdoor natural green space.

2.20 A diagnosis of dementia is often followed by a loss of a driving licence. This can mean that people become dependent upon the goodwill of others, or upon public transport which, if it is available at all, can be costly, inconvenient, and not always easy to use. This can become a significant contributor to isolation (as well as the attitudes of some family members):

“My son has got a car, but no, I stay indoors most of the time, they go out and they don’t like sometimes taking me so I stay in my bedroom.”

Participant

2.21 Most people talked in terms of how difficult it was to get transport, especially if there is reliance upon public transport or upon others.

“Participant A”: I haven’t got any transport, [name] hasn’t got a car

“Participant B”: [name] hasn’t got a car either.

Facilitator: Buses - are you able to use buses?

“Participant A”: I wouldn’t know which ones to get on and that, so that worries me.

Facilitator: Trains - when was the last time you were on a train do you think, do you ever get a chance to get on a train?

“Participant A”: 4 or 5 years ago.

2.22 **Signage, navigation and orientation** are widely regarded as important factors in determining accessibility for people with dementia - and this has been reflected in the comments of participants (14% of references). Useful signage and maps were referred to a number of times. Some of the issues with signage included size:

“Can I just say that probably one of the most important things I can see would be on these public footpaths that we walk along, if anybody is walking along there that’s not in our group, but just wants to go out for a walk and they have dementia, it would be so much better if the public footpath signs are increased in size so that when you are on one side of the field you can see the one at the other side of the field.”

Participant - Canterbury

Visibility of signage was also an issue:

“On the other hand people like the Woodland Trust all these signs blend in with the woods so they are green and brown so that they don’t stand out.”

Participant - Canterbury

2.23 The location of signage was important. Signage needs to work all the way from point A to point B rather than being absent at key decision points:

“You think well I have just walked past that sign, why didn’t it point me on the way in rather than when I am on the way back out again. There’s the sign. So there was issues raised about signage around here and there.”

Participant - Reading

2.24 Being able to work out where they were in an environment (orientation) was cited by several participants. People mentioned the importance of maps, but most often the addition of a simple ‘you are here’ arrow to allow the person to orientate themselves:

“I went to a new country park and was trying to find my way to the toilet - and they had a big map sign by each entrance...lots of ways in...it really was nice - everything laid out except nothing to show you where they were. Sometimes I think that people just need to see it from the point of view of people who are new to a place - and that’s the thing with dementia - you are new every time you go - it never gets boring (hahahaha).”

One to one interview - participant from Kent

2.25 **Information** was mentioned eleven times (14%), chiefly as a barrier to access. Most people were focused on difficulties getting information, rather than problems with the accessibility of the information itself in terms of layout or plain English:

“Unless you stumble across something, or already know about it, I don’t think there is an awful lot put out to the general public for people who just walk by to spot something, unless you actually investigate what you could access. I don’t think there is anybody physically going out there and saying, oh by the way you lot do you know you can do this and do you know you can do that.”

Participant - Reading

2.26 **Accessibility** was however an issue for one participant - making the point that written information accessible to people with dementia is also easier for everyone else:

“They have notices up sometimes and the writing is far too small, you know it may say about birds that are in the park but often the writing underneath is so small...you would have difficulty reading it and it needs to be simplified...I definitely think that it’s not just for older people but it is for children as well, because they like to read information and things.”

Participant - Redditch

2.27 **Refreshments** – having cafes or places to eat or drink - were cited by several participants. People talked about the importance of cafes in particular as places of shelter from the weather, providers of sustenance and treats, as a focal point for orientation, as a gathering place for a community, and to provide a focal point for the day:

“If rain comes down there are many activities, people like to treat themselves so they like to have some facilities with refreshments” [lots of agreement in the background from other participants].

Participant - Stockwell

“Some of these places you go to apart from this place where you can go and have refreshments there is always somebody.”

Participant - Stockwell

“Whereas at Martin Stanley Park there is no toilet facilities or café. So that prevents people from wanting to go.”

Participant - Redditch

One participant in Stockwell - a group for whom city parks were most significant - raised the issue of drinking fountains, and their demise. She said, to much agreement, that she found it difficult to carry water and that it was much easier when there was ready access to water through drinking fountains.

2.28 The need for **better access for people with dementia who also had physical disabilities** was mentioned seven times and included comments about the flatness of terrain, presence of physical obstacles, location of parking, and distances involved. There were also references to the importance of seating, toilets and safe walking or cycling routes, so taken together this group of issues was referenced 23 times (30% of references).

2.29 It is significant that 61% of people with dementia have three or more other health conditions (Fillit 2000) and that for many people with dementia these other conditions have more impact (such as physical mobility or sensory impairments) than dementia, particularly in the early stages of dementia.

"I think the thing with the lake is that it is an incredibly accessible area, the parking is great, it's great for all people of all mobility's, you have got the toilet facilities, cafe, place where you can have a rest."

Participant A: *"They don't have toilet facilities there"*.

Participant B: *"Oh they do but you have to search for them"*

Participants - Redditch

2.30 These quotes illustrate that although facilities are sometimes present in managed natural environments, they are not always easy to find. Some people with dementia will have different needs: some, for example, have problems with their sight which make it hard to read any signage unless it is in large lettering; others may need support both physical and emotional, from another person, to enable them to locate what is there. The planning and design of future projects needs to take into account the importance placed on the availability, siting and design of facilities.

2.31 **Seating** was an important issue as a necessary place of rest, to break up or act as a waymarker for a longer journey, and as a pleasurable place to admire a view, eat a packed lunch, or just to 'be':

"I do a lot of walking as it is also nice, if there are chairs and seats there and if there are parks, it is just nice to also look at where you are without walking. I think that's my, our park hasn't got seats, I still go there but [seats would be nice.]"

"That's basically what it is, where you can sit down and admire the place without too much effort."

Participant - Redditch

"Another thing is you know when we go to parks or anything, Prospect Park is pretty good because, just off the main pathways there are seats, but a lot of the parks there are no seats at all, just a piece of wood, you can't call it a seat. I mean with the parish council I said to them about more seats but they are reluctant to put seats because they say that the youngsters congregate where these seats are, whereas they can't get comfortable on one of these bars."

Participant - Reading

2.32 Given that many people living with dementia have mobility problems, seating is a key aspect of making green spaces more dementia-friendly.

2.33 **Toilets** were mentioned by several participants with availability, location, and signposting all being cited:

“Sometimes there might be toilets there, but they are a mile and a half down through the park somewhere but some people can’t go a mile and half, if they want the toilet they don’t want to have to walk up a mile and a half to get to it.”

Participant 1 - Reading

“Yes because it gives that person confidence to be able to walk a bit further knowing that, I can get that far because there are facilities there, when you don’t know you hesitate and perhaps don’t go that way.”

Participant 2 - Reading

“You are not so inclined to go that way, no I am not going down there because I don’t know how long I can go before I get back.”

Participant 3 - Reading

2.34 These quotes highlight that people need to know where they are at any one time and where they can find particular facilities and how long it will take them to get there.

2.35 **The support of others** (individuals and organisations) for people to engage in nature elicited the second highest level of responses from participants (25% of references) twelve participants talked about organisations that had been helpful or unhelpful, or said that it would help if more support were available from them.

2.36 Things that people found helpful from organisations were mainly focused around the friendliness and helpfulness of staff and volunteers, and the consideration and thought that had been put into the way a service works. Others mentioned specific organisations that provide support:

*“We are lucky enough to have Younger People With Dementia charity in ***** West who manage to get [name] into a canoe, two canoes strapped together for stability, which without that he would have sat at home.”*

Participant’s supporter - Redditch

2.37 A focus group participant from Canterbury runs a local walking group and has found ways of ensuring that people with dementia can participate:

“Because doing that you see we all stay within the group. Sometimes there is one particular area that I can think of where between the front and the back there is roughly ¾ of a mile which is why we use walkie talkies between the front leader and myself.”

“What we do is to tell her that we know where we are and that you’re ok, or you are walking well and if I reach that age I hope I can walk as fast as you because quite often she starts off at the back and ends up at the front.”

Participant - Canterbury

2.38 When people talked of the problems with organisations, it was mostly focused around unhelpful staff, volunteers, or systems which caused a barrier. Two participants spoke about booking systems which either required one to be online - or to be able to respond very quickly to a first-come, first-served system.

“If they are going to do a walk, let’s say a beach walk at Whitstable or a beach walk at Dover, you will have probably 20 places, out will come a newsletter there will be a 5 or 6 sentence explanation about the walk what it is going to entail who is leading it, its date and so on and so forth. If you don’t apply within a day or two you won’t get on it. So it would help if there were some kind of understanding of the difficulties not just for the dementia phase but maybe a range of other issues that members have.”

Participant - Canterbury

2.39 However, most responses were focused on individuals, and how they supported engagement. Most participants spoke very warmly about the support they had from individuals - with thirteen participants describing people as helpful. However, there were three references to situations in which people had not been supportive:

“I went in that entrance and I came out the other entrance and I hadn’t a clue where I was, I was absolutely crying because I just didn’t know where I was. I had to ask, there were a couple of people walking about, they laughed at me cos I didn’t know...”

Participant – York

2.40 For ten participants the mere presence of other people was important, as illustrated by this quote:

“I go out in Brockwell Park for a little walk, stroll and I see, what do I see, I see families having their picnic on the grass, weather permitting, you know, people walking their dogs, some are going to the lido for a swim or exercise, a whole variety of things...but you are surrounded by people. I know how important it is from direct experience that people, we humans, we need other humans, and we need them like hell we need them, you know.”

Participant - Stockwell

Four participants in Stockwell mentioned the deterioration of the park and a subsequent loss of sense of security and safety.

2.41 Perhaps most significantly when people talked about what really helps, and would help, the phrase “someone to take me” or words to that effect were used by ten participants across the groups.

Facilitator: “Ok and if you don’t have someone to go there with can you go there?”

Participant 1 “NO - I would get lost.”

2.42 People spoke with gratitude about the help that they received. But they also spoke about feelings of guilt, and some clearly felt that their needs were a burden to those around them. For many therefore, the notion that they might have support from others outside of their friends and family was an attractive proposition.

2.43 **Personal attributes and feelings** accounted for 20% of references to a range of personal factors that caused barriers to their engagement. The issue most commonly cited was difficulties with mobility and tiredness. As noted above, 61% of people with dementia have three or more other health conditions - and the data from the groups suggests that these are perceived to be a more significant barrier to engagement than difficulties caused by dementia.

"It's a long time since I have been there I went to the Forbury Gardens and I suddenly realised what we are actually missing because the paths are beautifully smooth and flat, there are benches every so many feet."

Participant - Reading

"I couldn't tell you the last time I went on a train. But it is getting on the train with my walker (that is the problem)."

Participant - York

2.44 **The effect of dementia** was clearly an issue however, with eleven people referring to it as a barrier. Nine cited a fear of getting lost as the main difficulty that dementia presents to their engagement in the great outdoors.

Facilitator: "What about experiences like paddling, feeling the sand between your toes?"

Participant 2: "Yes but you are going to a place that you don't know where you are and that's scary."

Facilitator: "So what could we do to stop that being scary?"

Participant 2: "It's scary because I might get lost."

York Group

Two other participants mentioned concerns about the reactions of others, and their reactions to them.

2.45 It is particularly interesting to note that restrictions caused by physical impairments were cited more often than those relating to dementia (though again - there are crossovers here as the effect of co-morbidities can be difficult to untangle).

2.46 Six people mentioned or alluded to a feeling of being a burden to others or of not liking to ask for help.

"Well my daughter is my carer and she volunteers to do most things every day, if she can't because she runs an organisation to help young people and therefore to get here she has got to get me here and go back to her organisation."

Participant

2.47 Fear of crime was an issue for two members of the Stockwell group. It was mentioned during a conversation about the demise of park-keepers. Conversely, one member said they enjoyed sitting with the “drinkers” in the park:

“They will always dance with me and like a conversation.”

Participant - Stockwell

2.48 As noted above, a number of participants were interested in talking about what they did **activities (something going on)**, as opposed to where they did it. The availability of activities, or lack of, was also referred to as an important factor in preventing or promoting engagement (16% of mentions). Many talked about the attraction of specific events or activities, or facilities to add extra value to their experience. Several people also gave the sense that an activity somehow framed the experience, or gave them a “reason to go” or a sense of “something going on”:

“Well we have got a car obviously and so we do go out quite a lot and try and go somewhere we haven’t been before, to try and find something new, to walk around, and somewhere hopefully where you can stop and have a walk as well, have lunch or something and make more of a day of it rather than just a little short stay.”

Participant - Redditch

2.49 In terms of activities that encouraged people to get out into green space the two most common themes were guided walks and social or communal events in green space. Six participants mentioned how much they enjoyed or would enjoy learning more about local history as part of their guided walk - especially in parks. The following quote illustrates what can be enjoyed about this.

“There is a meeting point, you arrange, it costs a little bit but it is not expensive and then you are taken on a walking tour and told this is where King Charles II had his head chopped off...it is very...this is a bit of history this, Brockwell Park and many of the other London parks during the Second World War huge areas were turned over to allotments. I remember as a boy.”

2.50 Other people enjoyed listening to talks, even if they weren’t sure where they had heard this:

“...when we got there, it was a speaker and everything goes on you can hear through the speaker, you can hear it from the speaker talking about everything. I can’t remember where this place is.”

Participant - Stockwell

A third person had enjoyed being reminded about the history of the town where they lived:

“With Forbury Gardens of course there’s the lion and no-one knows what the lion represents, and it is monument to the dead in the Afghan wars and there is 500 who died in 1830...you know because with Reading, with migrants coming into Reading, but also not just Reading itself but further afield in the 1930s, lots of Welsh people came and gave meaning to the transfer of labour. Anyway it is just a thought you know.”

Participant - Reading

2.51 Social or communal events were cited by 13 people. Music was mentioned by seven people, with some wondering about the demise of bandstands:

“Music is a great pastime...well I think that the one (bandstand) in Brockwell Park it is still used because it is always having concerts and things...I went there, but I can’t remember what it was, but it was quite good.”

Participant - Stockwell

“As a child my father loved to go on a Sunday for a walk after Sunday lunch and me and my sisters would have to obediently follow him and then we would finish up at the bandstand and they had a proper full brass band in the summer, all summer, it may have been the salvation army but whoever, it attracted, it even had sort of seats laid out ready for people who would love to go and listen to the music and in the surroundings of a great garden you know, all these things around you and it was a very peaceful sort of activity too.”

Participant - Stockwell

What would people with dementia like to do and what would help make that happen?

2.52 The last question that people living with dementia were asked, led to answers that are potentially central to help inform any future project. This focused on what people would like to do and what would help to make that happen, and this links across to the carers’ survey and interviews, where many of the elements that people living with dementia asked for were supported by views from carers.

2.53 The response of many to this question was mainly focused on the desire to be supported to continue to do what they enjoyed for as long as possible. In order for this to happen the general consensus was along the lines of “more of the things that help and less of the things that don’t”, although a number of specific issues were mentioned as being of high importance including:

- “Someone to take me”
- Transport
- Events to “add value” - especially guided walks
- Improvements to signage
- Better, more widely available information
- Better awareness of dementia

2.54 A small number of participants expressed an interest in taking up new activities or new opportunities. Specifically mentioned were:

- Using an outdoor gym
- Going to the seaside
- Sailing or boating
- Cycling

Facilitator: If we could magic up a trip to the coast to paddle, to feel the sand between your toes you would be up for that would you?

Participant: Ooh yes.

Facilitator: How about walking through a forest, crunching through leaves.

Participant: Ooh yes that would be wonderful.

York Group

This quote illustrates the potential that people living with dementia have to explore places outside of their everyday environments.

Summary of key findings from people with dementia

Activities

2.55 People are more engaged by activity than by place and this gave them a “reason to go” or a sense of “something going on”.

2.56 The most popular outdoor activity reported was informal walking. 38% of people with dementia identified this as an activity they enjoyed.

2.57 People living with dementia said that activities that motivated them to get out into green space were: guided walks and social or communal events in green space. Almost a third of people living with dementia talked about the importance of guided walks in encouraging them to get out into green spaces, and nearly 25% talked about the role of social or communal events, especially in parks: for example, talks about local history, or listening to music at the bandstand.

Places

2.58 Spending time in managed environments (e.g. parks) is a far more important motivator for visiting the natural environment compared to less intensively managed areas.

2.59 The presence of water at the location was an important motivational element for approximately half of the people with dementia, not just specific sites like canals, but in terms of the attraction being close to water. This could be a fountain in a park, for example, or a lake.

2.60 After places involving water, parks or public gardens were second most popular, with 30% of people with dementia referring to them.

Key factors that help or hinder engagement

2.61 The available facilities at a site (e.g. signage, refreshments, toilets and physical access), were the most significant factors in determining the frequency and preferred locations for visiting the natural environment.

2.62 The availability of support from others at a given location was also a significant factor. When people talked about what really helps, and would help, the phrase “someone to take me” or words to that effect were used by ten participants across the groups.

2.63 Personal attributes and feelings were also important factors. Difficulties with mobility, tiredness, the effect of dementia, and the attitudes of others could all affect peoples’ engagement with outdoor activity.

2.64 Support from other people, whether individuals or organisations, was valued when this was offered in a sensitive way.

2.65 The main barriers to participation in nature or outdoor activities, according to people living with dementia, are transport, confidence and ‘someone to take me’.

2.66 Given that transport is a barrier for people with dementia visiting the natural environment it further explains why they prefer to visit their local parks, rather than travelling further afield.

2.67 There was an emphasis on outdoor settings and activities needing to adapt to be inclusive of people with dementia, rather than people with dementia having to try and fit in with the settings and activities.

2.68 People want to be supported (by dementia-specialist services) to continue to do what they enjoyed for as long as possible.

3. Findings from the carers' survey

Quantitative findings

3.1 The online carers' survey was primarily aimed at identifying whether people living with dementia engage in nature on their own or with support, and what support is needed. The objective therefore was to gather information from carers on the following themes:

- Identifying the level of outdoor activity people with dementia take;
- Their reasons for engaging or not engaging with outdoor activity;
- What people with dementia and their carers would like to do outdoors;
- What green spaces can do to become more 'dementia friendly'.

The questions were mostly structured, leading to numeric or quantitative information. There were some open-ended questions too, and this qualitative data is reported in paragraphs 3.44-3.77 below.

3.2 A target of 125 respondents was set for the carers' online survey. This was exceeded as 172 people responded to the survey although not all respondents completed every question.

Respondent demographics

3.3 Over half of carer respondents lived in either towns (29%) or villages (27%); the rest were spread between inner cities (15%), suburbs (18%) and rural areas (11%). The terminology was not defined, so some people may have meant different things by 'towns' or 'villages'.

3.4 The overwhelming majority (nearly 90%) lived in England, with just a few respondents from Scotland, Wales or Northern Ireland.

3.5 Almost four out of five respondents were female (79%).

3.6 Over a fifth (28) were aged 65 or over. Nearly all of the remaining respondents were aged between 40 and 64. The average age of respondents was 53.

3.7 Out of 165 respondents, 136 described themselves as being English (82%). Of the remainder, 17 described themselves as being Scottish, Irish or Welsh; 4 as 'other European' and 6 said that they were either African, Asian or Caribbean descent. Two people preferred not to say.

Relationship to person with dementia

3.8 The survey was primarily aimed at carers who were family members or friends: however, only half of the people replying spelled out their relationship to the person with dementia. For this half, the vast majority were carers, although some had experience of professional caring roles as well. Given the networks through which the survey was

distributed, it is probably safe to assume that this was the case for most of the other respondents.

3.9 Of the 81 people who replied to this question, 65 people were family members (80%). Of these, 42 or about half were caring for a parent or parent-in-law, and 16 (about one in five) were caring for a spouse. The remainder were caring for a grandparent or sibling. 10 people (12%) had professional relationships with the person with dementia, for example as a day service manager or part of a social enterprise where older people support other older people. One respondent was completing the survey about residents in a care home. The remainder (7%) wrote 'other' apart from one person who was completing the survey on their own behalf as a person with dementia.

People's relationship to nature spaces

3.10 People were asked about how far they lived from the nearest of a series of different types of nature spaces. 161 people answered this question. Table 1 illustrates this data.

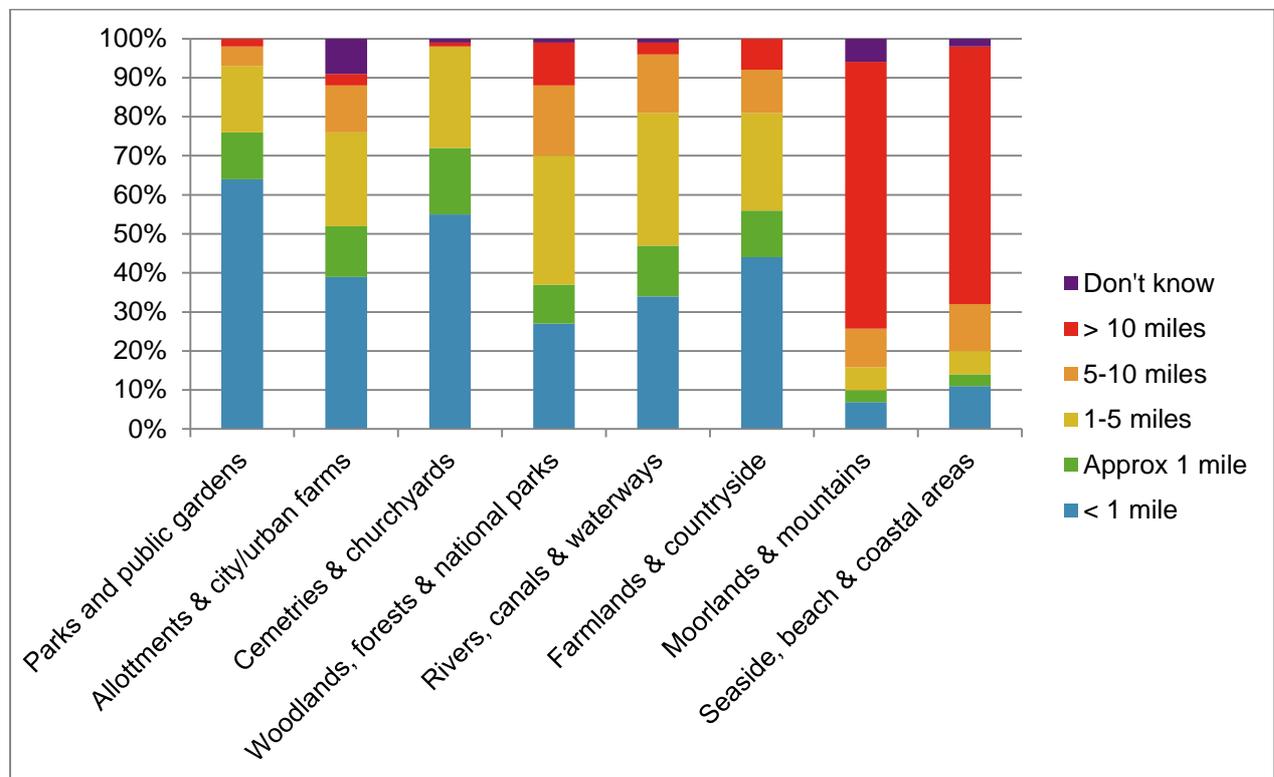


Figure 4 Distance lived from nature space

3.11 The data from Table 1 was analysed along with what carers reported about how often people with dementia visited different types of outdoor space. Figure 4 summarises these frequencies, with the blue columns showing how many people visited places more than once a month; the red column how many people visited less than once a month; and the green column showing how many people never visited the various types of spaces.

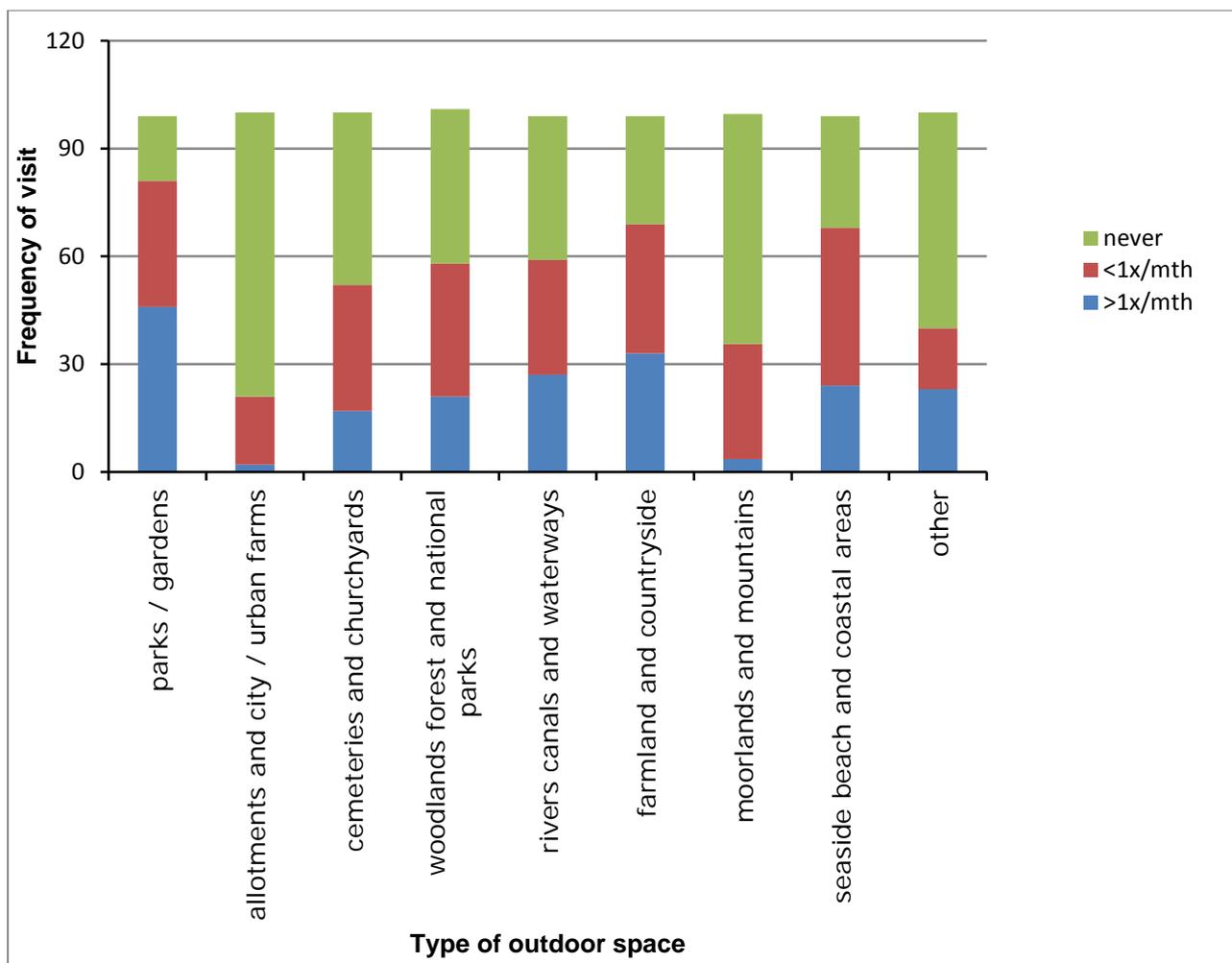


Figure 5 How often people with dementia visit different types of outdoor space

3.12 Almost two thirds of respondents said they lived less than one mile away from a park or public garden. These were the most popular places to visit, with nearly half of people replying saying that the person with dementia visited a park or public garden at least once a month. On the other hand, more than half of people with dementia were said to visit such spaces less than once a month or never. There were 13 people who visited these several times a week and one person every day.

3.13 Almost half of respondents lived close to farmland or countryside. These were not defined: countryside may have been interpreted differently by different people. The figure doesn't quite tally with that of the number of people living in villages or 'rural / countryside'. Farmland and countryside were the second most popular place to visit; carers said they were visited at least once a month by a third of people with dementia. This makes them relatively popular compared to other outdoor spaces that were visited less often. The remaining two thirds of people with dementia were said to visit them either less often than once a month, or not at all. Seaside and coastal areas were also popular, visited at least once a month by a third of people with dementia, though less often compared with farmlands and countryside.

3.14 Four out of ten people replying lived less than one mile away from allotments and city or urban farms, yet the vast majority of people with dementia (80%) were said to never visit them.

3.15 People's proximity to national parks, woodland and forests varied. Four out of five people with dementia were said to visit them either less than once a month, or never.

3.16 One third of people said they lived less than a mile away from a river, canal or waterway. Three quarters of people with dementia, however, were reported as visiting them less than once a month or never.

3.17 Two thirds of people lived more than ten miles away from moorlands or mountains, so perhaps not surprisingly hardly anyone visited them more than once a month, and two thirds of people - never visited them at all.

3.18 Two thirds of people lived at least ten miles away from the seaside, beaches or coastal areas, and a similar proportion (75%) rarely or never visited them. There was however a small number of people with dementia who visited such spaces frequently and nine people visited them once or more a week.

3.19 Finally, over half the respondents lived close to a cemetery or churchyard: most people however, rarely visited them.

3.20 Although it is not possible to directly compare these findings with the national survey on people's engagement with nature published by Natural England ('Monitor of Engagement with the Natural Environment') because different measures are used, it is possible to make some general comparisons (Natural England 2013). MENE indicated that the majority of locations visited were either to the countryside (47%) or green spaces within towns and cities (43%). Although reported visits more than once a month by the person with dementia to parks or public gardens was roughly comparable with MENE it was significantly less for visits to the countryside.

Person living with dementia demographics

3.21 People were asked how long the person, about whom they were completing the survey, had been living with dementia. Over half of those who completed this question (n = 128) said that the person had been living with dementia for between one and five years (53%). Most of the remaining people were reported as having lived with dementia for more than five years.

3.22 Nearly two thirds of people about whom the survey was completed had either Alzheimer's disease or vascular dementia. Quite a lot of people chose not to respond to these questions which may reflect a hesitation in thinking about the person with dementia in this way, or they may not know.

Limiting factors on visiting nature spaces

3.23 Carers were asked if they had any health conditions or a physical disability which limited their ability to visit nature spaces. Four out of five people said 'no', the other fifth said 'yes', but as this was a closed question we do not know what the condition or disability was.

3.24 Respondents were then asked to what extent they agreed with three statements about the ease with which they could visit outdoor spaces. Most (82%) agreed or strongly agreed that it was easy for them to visit nature spaces on a regular basis. However, almost as many agreed (69%) that as a family carer they needed support to enable the person living with dementia to visit nature spaces. Most agreed or strongly agreed (73%) that it was easy for them to find information about outdoor activities and nature spaces.

Effect of dementia on person's ability to use outdoor spaces

3.25 Of the 125 who answered this question, 104 (83%) agreed that the dementia did limit the person's ability to use outdoor spaces, in marked contrast to the views of people with dementia who took part in this consultation (where only 20% thought their dementia was a barrier to their ability to use outdoor spaces).

Other health conditions or physical disabilities limiting the person with dementia's ability to use outdoor spaces and nature

3.26 Just over half of the 121 people replying to this question said that the person living with dementia had other health conditions or a physical disability that affected their use of outdoor spaces and nature (which is fairly consistent with the figure cited on page 30). As this was a yes/no question we did not know what the condition or disability was.

How often the person living with dementia usually participates in various outdoor activities

3.27 Respondents were presented with a list of various outdoor activities and asked to indicate how often the person with dementia took part in these. The chart below shows the popularity of these activities.

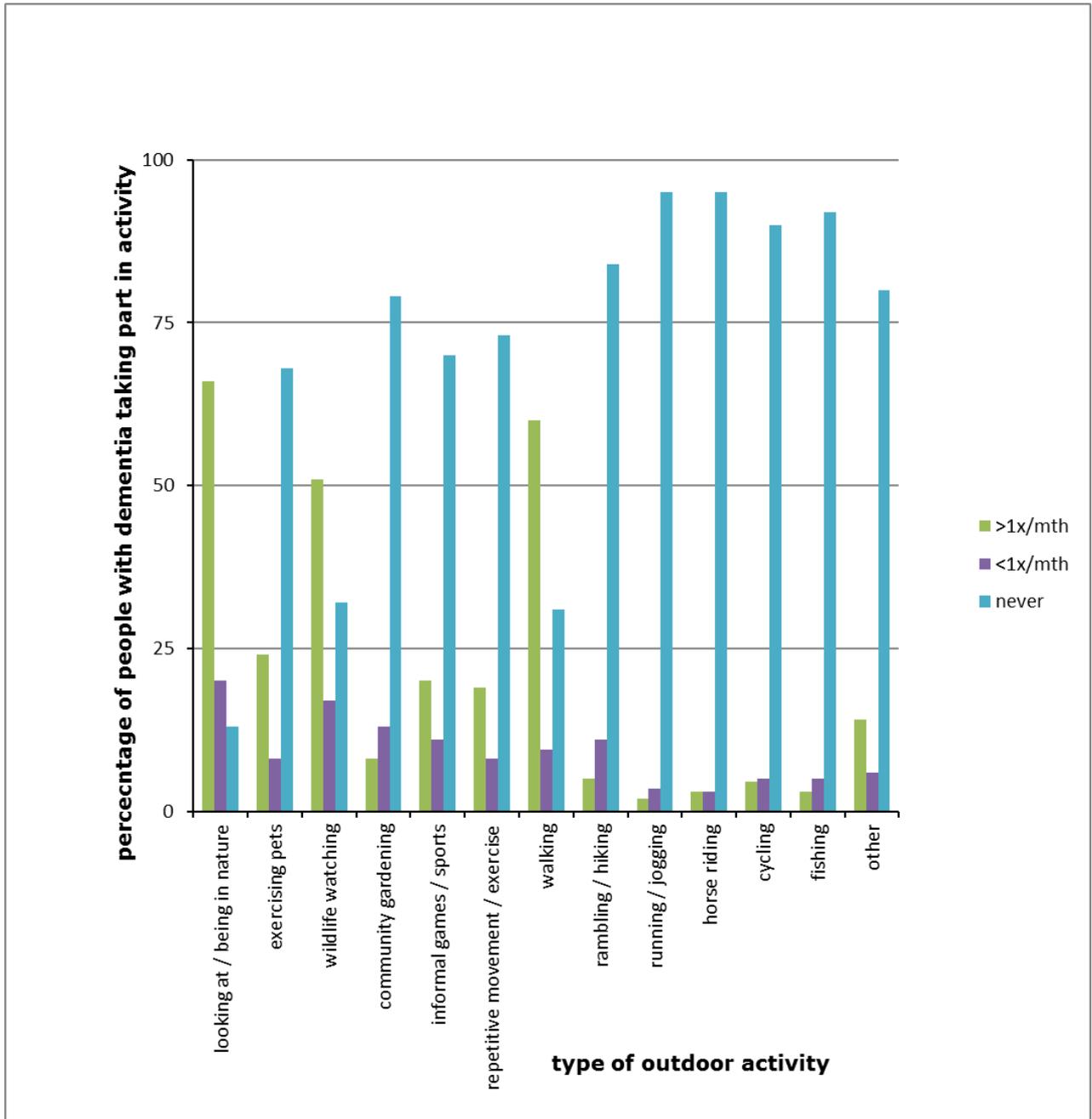


Figure 6 Frequencies of taking part in outdoor activities

3.28 There were three types of activity that came out as being much more popular than the rest. ‘Looking at or being in nature’ was by far the most popular, with 38% of people with dementia said to do this several times a week or every day. Next was walking, which 33% of people with dementia were reported as doing at least several times a week. Thirdly, wildlife watching was also very popular, although it happened less often than the first two. Here, 25% of people were said to take part in it several times a week or every day.

3.29 Other activities were reported much less frequently as being popular: with exercising pets fourth in popularity, with 13% of people with dementia doing this several times a week or daily. The other activity whose popularity is perhaps surprising, is repetitive movement or

exercise (e.g. yoga, tai chi, aerobics), where more than one in ten people were said to do this at least once a week.

3.30 All remaining activities listed had very small numbers of people taking part in them frequently, most people being cited as not engaging with them at all.

What sort of activities the person with dementia would choose to take part in if the right support and information was available

3.31 This question sought the views of the respondents about what outdoor activities the person with dementia would choose to do if the right support and information was available. The figures are consistent with what people already do i.e. on the whole they would choose to do the same things that they currently do (78% would look at or be in nature; 60% would watch wildlife; 49% would do some walking).

3.32 The major exception was community gardening or farming. When asked how often people with dementia currently take part in this, the vast majority (79%) were said to never take part in either of these. However, when asked what they would do if the right sort of support and information was available, respondents said that 28%, or almost one in three, of people with dementia would choose to participate in one of these.

3.33 There was also a notable difference for informal games or sports, in which 70% of people with dementia were said to currently never take part, while with support and information 20% or one in five would do so.

Barriers to the respondent (carer) and the person living with dementia participating in outdoor activities and nature

3.34 Respondents were asked about possible barriers to themselves and the person living with dementia taking part in outdoor activities and nature. They were given a list of statements about particular possible barriers and asked to rate how far they agreed or disagreed with these statements. Figure 6 below shows how people responded to this question, giving the percentages of respondents and how far they agreed with the various statements.

3.35 The three top barriers to people taking part in outdoor activities and nature were:

- lack of confidence;
- fears and safety concerns; and
- transportation.

3.36 Three quarters (74%) of people agreed or strongly agreed that a lack of confidence was a barrier to participation. Almost as many (73%) said the same about fears and safety concerns. Transportation was a close third, with 68% of people agreeing or strongly agreeing that this was a barrier to them and the person living with dementia taking part in outdoor activities.

3.37 Around half of the people responding agreed or strongly agreed that not enough information, a lack of spare time, and nature spaces not being accessible, were barriers to participation. However, far fewer people strongly agreed about these than did about the top three barriers.

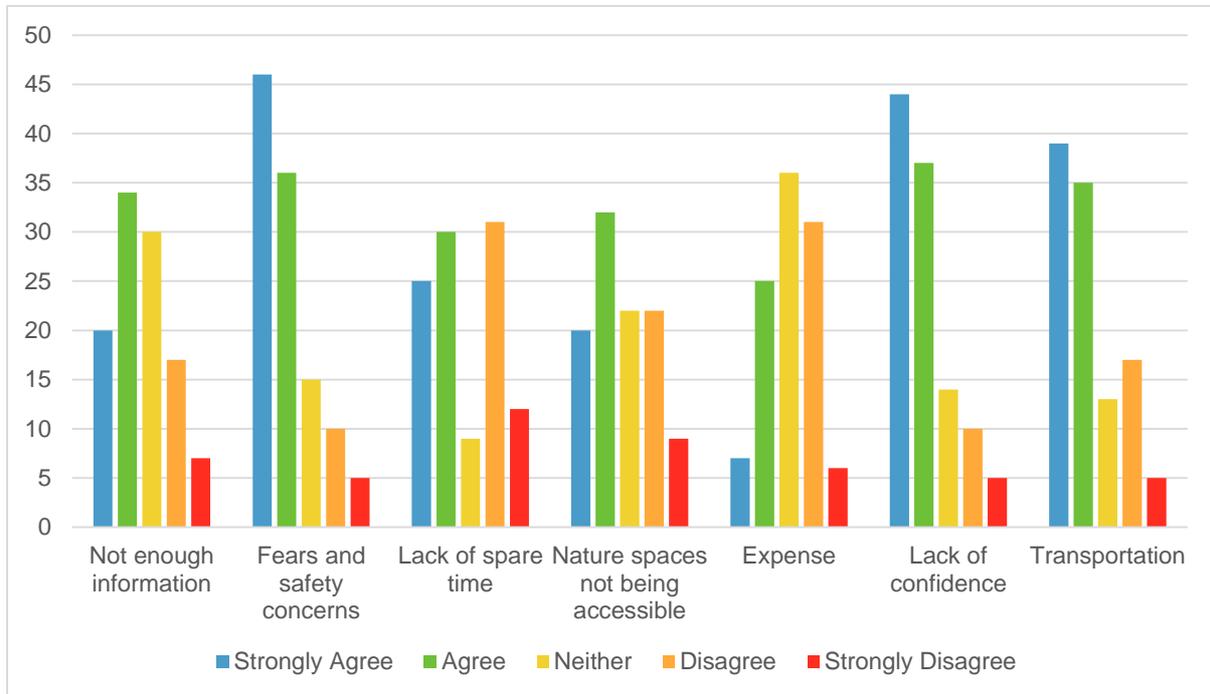


Figure 7 Existing barriers to outside space for people with dementia

3.38 Carers' views on nature spaces not being accessible, which might be expected to be a significant barrier, were evenly distributed across the rating scale, meaning that 40% of people either felt neutrally about this statement, or disagreed with it.

3.39 Not many people (31%) saw expense as a barrier.

Views about the benefits of and barriers to people with dementia taking part in outdoor activities and nature

3.40 For this question people were asked to rate a series of statements about different aspects of people with dementia taking part in outdoor activities and nature. The full statements are set out in figure 7 below.

3.41 Four out of five people agreed that regularly taking part in outdoor activities and nature is beneficial for people who are living with a dementia. However, almost two thirds agreed that it was difficult for people living with dementia to do this. Most (76%) agreed that dementia-specialist services are needed to support people with dementia to take part in outdoor activities and nature.

3.42 Two thirds disagreed that is easy for people who are living with dementia to access support and information about participating in outdoor activities and nature.

3.43 Over 40% of respondents neither agreed nor disagreed that people who have a dementia would prefer to participate in organised group activities in nature and it was fairly evenly balanced between those who either agreed or disagreed with this statement.

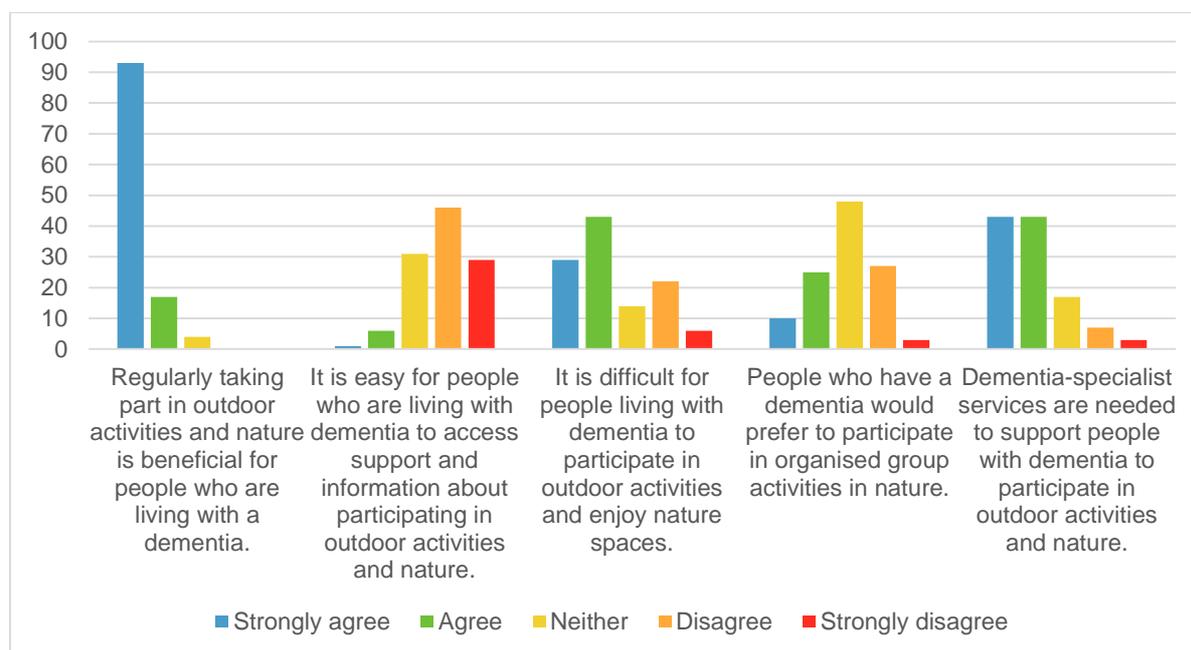


Figure 8 People with dementia taking part in outdoor activities and nature

Qualitative findings

3.44 The second part of the survey was qualitative: carers were asked to give their views about a series of aspects of the relationships between people with dementia and nature. The results are summarised below.

How dementia has affected the person’s ability to use nature spaces?

3.45 This was an open-ended question with space for people to write their own comments. This led to a number of themes recurring throughout people’s answers. 98 people made comments. The results need to be read with a note of caution as the responses were based on a third party’s view of a person with dementia.

3.46 The first and most dominant theme was around **mobility**, people with dementia having restricted mobility in one way or another. It was not always clear whether this was as a direct result of their dementia or for other reasons. Thirty people were said to have restricted mobility, quite lot of these finding surfaces other than flat or steady surfaces, difficult to negotiate. Examples of this were one man who found it hard to find his footing on uneven terrain; another who was uncertain about climbing stiles or fences; and a third person who would only go on paved surfaces. The man who struggled with his footing was afraid of crossing cattle grids, because he wasn’t confident about his balance.

3.47 Eight people had to use a wheelchair to get around: one of these apparently didn’t believe that she needed a wheelchair so resisted going out in this way as she thought she could still walk.

3.48 **A lack, or loss, of confidence** was another theme that came through strongly from people's answers. Ten people were reported as experiencing a loss of confidence. Linked to this was a reluctance to leave home. One person was reported as not wanting to leave home at all, while nine others were reported as not being able to leave their homes independently or without support. One person was said to have no self-confidence for trying out new things, while six others were reported as getting lost easily when on their own. Seven more were said to be unable to find their own way to places and return home. One respondent reported that the people they supported "*are at risk of getting lost in nature spaces, even those they have known for many years.*"

3.49 Five people were reported as having problems with spatial awareness which affected their confidence in going out.

3.50 Several people were said to get easily **confused or disorientated**. Two couldn't remember where they lived if they went out; another needed someone '*to keep an eye on them*' when walking so that they didn't get distracted. One person was confident walking to and from church, or using familiar lanes, '*but would be lost in unfamiliar places.*'

3.51 A number of people completing the survey reported **fears or anxieties** in the person with dementia. Three people were reported as being scared to go out; two more as having general insecurity; one, a fear of getting lost; and another a fear of woodland trees and darkness as this meant they couldn't see where to go. This person was fearful of going anywhere new, and even experienced places with which they had once been familiar as new.

3.52 Five people were reported as being anxious about new and unfamiliar places, with two more being said to have a fear of crowds and noise. One woman '*can no longer cope with lots of noisy people*'. Another was said to be afraid of others' reactions to them. One carer contrasted her mother's anxiety about crowds and noise, and her unsteadiness and vulnerability, with the things she really enjoyed:

"On the positive side she really loves watching and commenting on clouds and trees and light. And watching young children playing"

3.53 Five people were reported as struggling with **temperature**: one had an extreme sensitivity to the cold such that as soon as she was out of the door she wanted to go home again; while several others couldn't understand that it was cold outside so didn't want to put warm clothing on in order to go out.

3.54 Only two people made reference to the person with dementia's **moods or behaviour**, one saying that they were very rude or aggressive if they went out and that this made it difficult, while another said that the person they cared for '*had lost all sense of joy in life*' and that they were now very aggressive and negative.

3.55 Two people were reported as **having trouble breathing** when out and about: one was described as '*huffing and puffing*' while another person was said to get out of breath easily although it was not clear whether this was linked to their dementia.

3.56 Two people had had their driving licences revoked when diagnosed with dementia, and this had presented a barrier to them getting out as much. One person reported that while many places were wheelchair accessible, **transport** was still a problem.

3.57 One carer described how their father used to take their mother out and ‘to begin with, enjoying walking in Derbyshire and the local parks and walking by the river Trent. As the dementia decreased mum’s cognitive power the energy and patience required by father to maintain her interest became too much’. The person with dementia did continue to enjoy a decent quality of life after this, however, being later in a care home with stone lions similar to ones in the centre of the city where she lived, helped with her long-term memory.

3.58 Finally, one person reported on some of the cultural issues affecting their mother’s use of outdoor spaces. This person had English as a second language, so needed support from her family to access nature spaces otherwise she couldn’t find out where to go, or have the confidence to go on her own. A group set up by her daughter-in-law to support access to National Trust places, had helped her to feel more comfortable to visit spaces ‘*with links to British Imperialism*’.

Benefits of the outdoors

3.59 Several participants identified positive benefit, real and potential, of the outdoors and outdoor activity. One person said simply, “*for my mum the best change would be to move the mountains closer!*” Another pointed out that although not everyone liked outdoor activities or nature, for those who did, every effort should be made for them to continue doing what they enjoyed: ‘*support tailored to suit needs, regardless of cost!*’ A third person said that people with dementia deserved the opportunity to enjoy pleasant, uplifting surroundings. Easy access to quiet, beautiful outside areas would be very helpful to both people with dementia and their carers, in their view.

3.60 One family carer, writing about their mother who had been diagnosed with dementia several years previously, said that even with significant dementia she improved very noticeably when outdoors and walking: that she then talked more, noticed things around her and had a dramatic uplift in mood. Another person felt that greater exposure to nature could be a very welcome relief when other support measures were in place to make it a safe visit.

Finally, one person explained that:

“we all get a lot of pleasure even just watching the birds feeding and splashing about in the pond, and I’ve noticed that mum’s compassion and sense of connection with wildlife is now greatly heightened...I think that one of the greatest difficulties is to educate families, partners, carers etc. to focus on the potential of the present rather than the loss of the past.”

Types of support and information that would enable the person living with dementia to participate in outdoor activities

3.61 This was another open-ended question where people were free to write whatever they felt was relevant. A total of 77 people offered comments. One person, reflecting the views of a number of carers, summed up a key issue by wanting:

“...places to visit which offer simple activities (a comfortable place to sit and observe in pleasant surroundings – countryside / seaside) also ones which allow one of [the] daughters to be in attendance. No pressure to ‘participate’ in activities.”

3.62 Across the rest of the replies, there were a number of themes which ran through them. There were also some more replies which are described under ‘other’.

3.63 Fourteen people said there should be **a person available to help and support the person with dementia**. One or two people added to this, that the person needed to be from outside the family or someone with specific training. Eight people called for one to one support. One person spelled out what they felt was needed:

“Building up a daily relationship with a support worker who could slowly lead the person into the event.”

3.64 Nine people called for **accessible information**. Some made general comments about this while two people were specific about a need for information to be available for carers. Another person, however, didn’t feel that information made much difference:

“We have information but it’s the practical side of getting a grumpy and aggressive person who can’t walk well and who is in pain, to get in the car for a trip.”

This person felt that having a more proactive and positive GP would be a big help.

3.65 Nine people asked for transport to be available. Most people made a general comment about this, although one person asked specifically for a car and driver while another called for there to be:

“Limited-mobility friendly and dementia-friendly boat trip companies transport.”

3.66 A number of people talked about the need for the person with dementia to be **encouraged to take part, or to carry on taking part, in activities**. One felt this was best achieved if her relative could ‘see other people doing the activity and someone to give her lots of praise.’ Five people felt that the person with dementia would enjoy group activities.

3.67 Two people called for **on-site guides** to help support people with dementia as they went around. One person said that any facilitators of activities ‘would need to be able to...tailor the activity to the ability of each individual and where they are with the disease.’ They added that their mum loved to play ball games and table tennis but sometimes overestimated what she could do at the age of 90 because of the dementia.

3.68 Several people called for practical items that would facilitate people's participation in outdoor activities. In particular, six people called for there to be flat, wide, open paths. One asked for seating to be available, while another asked for resting places. One asked for gates with simple catches. Another asked for there to be ramps to walk on and handrails. One person specifically called for visual signs in colourful large design. This person also felt that people *'trained in non-verbal communication including visual, tactile, sensory including smells and music etc.'* would be a big help.

3.69 Two people called for **relief for carers**, to take some of the pressure off them. One person called for there to be activities organised at the weekends when they were available to support their relative to take part in these. Another person listed the main concerns for carers, these being knowing where to go, help with transport to get there, and support whilst at the venue.

3.70 Nine people asked for **better access to facilities or spaces**. Most didn't specify what sort of access they meant, although some indicated that wheelchair access was crucial. Five people wanted accessible toilets, for these to be more readily available in public areas, and one person wanted *'access to friendly low pressure environments'*. One person asked for a local community garden. Finally, one person said they would like *'additional carers to assist and a calm, friendly dog to borrow.'*

Other adaptations that might make nature spaces more dementia-friendly

3.71 This was an open-ended question where people could write their own views. 28 people made comments.

3.72 **Level walking paths** was an issue that came up in response to previous questions too. Six people stated that level walking paths were important. One spelled out that paths needed to be free from gravel or rocks too, *'as people with dementia lose confidence in their footing and often cannot see or respond to rough or uneven terrain.'* Another person felt that paths needed to have a wide verge clear of trees and large shrubs.

3.73 **Quiet places** came up in relation to other questions. Here, one person said there should be quiet areas not only for people with dementia but also for others who cannot cope with loud and noisy environments. In a similar vein, another person called for stopping points where people could sit and contemplate. There was again a call for more seating to be available, possibly with posters naming surrounding items such as flowers and trees.

3.74 **Car parking** was brought up by five people, several of whom felt strongly that this needed to be near to the venue (which it isn't always). One added that it would be good to have people who could help you if you needed help to get the person out of the car, while another pointed out that people's preferences may vary from day to day, so it would help to have parking close to nice, open spaces that people could enjoy watching:

"Some on particular days / times may prefer to sit in the car and observe."

3.75 A lot of people talked about the need for **sensitivity to fears** faced by the person with dementia in response to earlier questions. When replying about adaptations that would make places more dementia-friendly, one person poignantly asked for *'No narrow, dark places - bird hides entrances are too frightening for my mother'*.

3.76 **Trained staff** was again brought up in relation to previous questions. Here, several people called for staff trained in dementia awareness to be available at outdoor spaces, to assist the person with dementia and also to assist the carer. One pleaded for care for the carers, *'so that they can take a toilet break or tea break without fear of leaving the dementia visitor alone.'*

3.77 Other comments about dementia and outdoor spaces was the last question on the survey, and a chance for people to voice anything they hadn't already done so. 42 people made comments here, including:

- *Cultural barriers* - one person wrote about the additional burden imposed by cultural barriers that were rarely addressed in relation to dementia;
- *Tactile elements* - one person here called for more tactile elements *'and / or sensory gardens with old-fashioned flowers that the person may recall.'*
- *Indoor spaces* - one person suggested that indoor spaces where the person with dementia could go if they became anxious or if it rained, would be good;
- *Wildlife photography* - one person, writing about themselves, said that their wildlife photography had been their meaningful activity and their lifeline. They added that no help was sent their way until they insisted upon it and people humoured them.
- *Stigma* - one person reflected on the social stigma that can still be attached to dementia, commenting that:

'Friends often seem to disappear or not include people with dementia in social activities any more – often they just need a bit of support and kindness.'

- *Early onset dementia* - one person highlighted how younger people living with dementia may be able to contribute to an activity, not just attend, if given clear instruction and guidance.
- *Issues with social care* - one person said they had been better informed than local social care professionals, who had lacked information and networks, and asked them for contact details to get help for a person with dementia. Another said that social services should be supporting people to get the most out of life: *'outdoors is a necessity if only to breathe fresh air and see the sun.'*

4. Interviews with carers

4.1 The interviews with carers were structured around the main aims of the project, and led to a number of key themes arising and how these are relevant for future developments.

The role of the natural environment in helping people with dementia to be calm

4.2 From the interviews with carers, one key finding is that nature helps people with dementia to stay calm or to *forget about their symptoms*. So, for example, DEN8 said that her husband used to experience tremendous anxiety as he got more and more ill. The only thing she found that helped him was to go out:

'So we just used to walk the streets literally just walk round and round and round until he felt better and...it could be any time of the day or night and that really helped him to be outside... it helped him to calm down again and I don't know how it worked but it did I guess it just put his mind in a different place.'

(DEN8)

Later in the interview she remarked that:

'It was definitely preferable for D to be outside - he could be like a caged animal inside you know pacing, whereas outside he seemed to relax more, definitely.'

(DEN8)

4.3 A second interviewee talked about how walking would calm down his wife, who had dementia, when she was feeling agitated:

'There was always some sort of behaviour problems but at least by walking for a time as well as enjoying the natural things it calms her down.'

(DEN9)

This calming effect is something that has been found in other research. It may be that being in the natural environment helps people to forget about their symptoms, or brings a different rhythm into their lives.

The role of the natural environment: enjoying sports

4.4 Taking part in sports was an activity cited by one carer interviewee as bringing pleasure to people with dementia. She (DEN8), explained how her husband had once been a footballer and enjoyed taking part in five a side football. Friends used to take him along to play:

'...I mean we bought vests so that he knew what team he was on in theory but they put up with the fact he was just as likely to pass the ball to a member of the other team...and he was able to do that for a long time way past and that was really good, I used to think it was an activity he enjoyed and he still felt he was part of things you know, that relied on friends.'

(DEN8)

She was confident that this *'felt purposeful for him'*.

4.5 Another interviewee had been in a caring role for a man whom they found out had once been a professional runner. Sharing this knowledge had opened up conversation between them and led the person with dementia to ask to be accompanied to local sporting events.

4.6 Another interviewee talked about how the hospital where they used to work was right next to a football field, so staff could take 'guys' from the ward (apparently it was mostly men) to enjoy watching a football match. This hospital had relocated and was now too far away for this to be easily possible.

The role of the natural environment: being in nature

4.7 Being in nature was one of the three highest rating activities that people with dementia were said to enjoy, from the carers' survey. In the interviews with carers, this came up in different ways, with some people talking about the pleasure the person they cared for derived from just sitting and watching the world go by, while others were able to venture further afield. When they were able to, one couple went to the seaside for an outing. They lived only 20 miles from the coast. The interviewee herself found this helpful as it gave her something to talk about:

'Latterly we could go to the sea and walk on the beach and have an ice cream and...again that is something to focus on...it is not just walking for the sake of it there is something to look at you know something to talk about...he actually lost...most of his language ability, but it gave me something to talk to him about...I'd say...ooh there is a lot of seagulls today and...I don't know how much he actually got out of it, but it certainly gives you something to talk about and focus on.'

(DEN8)

Walking

4.8 The popularity of walking was an activity that came up in both the carers' survey and the carer interviews. Walking fulfilled a different role for different people. For some people walking was said by carers to be a pleasure in itself, while for others, as reported by people with dementia themselves, it was a means of getting to an activity or a place.

4.9 The activity of walking seemed to have a calming effect for some people with dementia, and this was a theme that also came up when people were talking about being in nature (see section above). It may be, as suggested by several carers, that this is because being in nature takes people with dementia out of their home environments where there may be restricted stimulation and where being confined may add to feelings of agitation.

4.10 As walking was an activity that had come out strongly from the consultation with people with dementia, and from the carers' survey, as something enjoyed by many people with dementia, carer interviewees were asked a direct question about this. For a few people, their restricted mobility meant that they weren't able to go out for a walk: for most people, however, (7 out of 10 interviewees talked about this), walking was something they enjoyed, whether on their own to a local park or other nearby nature space, or in the company of someone they knew who could support them, usually a carer or, in one instance, friends.

4.11 One carer's grandfather, who had been a shepherd as a young man, '*loved being outdoors and just going walking*' (DEN2). A second interviewee said how her husband, who had dementia, used to go off for walks: '*I felt it was the action of walking was therapeutic for him.*' (DEN5).

4.12 Some people with dementia were reported as enjoying walking with a group, while others went for walks with just their spouse or carer. Thus a third interviewee said about himself and his wife: '*When we were off walking...we were fine on our own really.*' (DEN7).

A fourth interviewee talked about how his wife enjoyed going out walking with him, and also on her own. If she went on her own he would track her and check whether she wanted him to accompany her home if she got lost (DEN3).

4.13 A fifth interviewee described how her husband used to really enjoy walking '*before he was ill*' and how she and some friends coordinated a whole system of support in the background to enable him to continue to do this for as long as possible. During this period of time he would leave the house by himself and get on the local bus, where the drivers would know where he had to get off and prompt him to do this. There would be friends to meet him at the other end and put him on the bus to go home:

'That was really important because it still gave him a sense of independence.'

(DEN8)

4.14 This arrangement came to an end following one occasion when her husband got off the bus in the wrong place and got lost, which was '*pretty scary*' so this way of supporting him to carry on walking had to end. Later on in his dementia, her husband was rejected from walking groups because they were afraid he would get lost or '*be difficult*' if he came to a stile. The interviewee's determination to support her husband to do things he enjoyed led her to ask two of the people who walked with the University of the Third Age (U3A) to take him out, which they did for some time (DEN8).

4.15 Walking was an activity also enjoyed by the wife of a sixth interviewee. When she was able to, this couple used to go regularly to Hyde Park or Regents Park, both of which were close to where they lived:

'I always make sure that she go for a walk for about an hour every day...it's sort of enjoying the environment open space as well as for health benefit.'

The husband went on to explain how his wife used to enjoy the sensory aspects of the park too, even when her dementia was quite advanced:

'...especially like in the Regents Park in the later stage it's a different sort of tactile difference floor surface cement, tar, grass and things like that...we had a rose garden and I would take her to different sort of shrubbery and different fragrance so that she would [enjoy]...sort of smell stimulation plus visual stimulation.'

(DEN9)

4.16 Another interviewee described how his wife would go out on her own for a walk sometimes, but how he would then track her on his bike in case she got lost or confused, in which case he could cycle up to her and ask if she was ok and if she wanted him to escort her home.

4.17 Clearly walking wasn't an activity that could be enjoyed by all, as many people with dementia have restricted mobility and are not able to walk unaided or supported.

Watching the birds / gardens

4.18 Gardens featured significantly in the lives of six of the people with dementia who lived in their own homes and had access to one. Access here meant both there being a garden available and the person with dementia being able to get out into the garden and enjoy it. Some (2) weren't able to get out into their gardens but still enjoyed looking at what was going on from inside their home.

4.19 It was sometimes hard to disentangle the garden theme from what people said about birds, both feeding and watching them, as this often happened in people's gardens. The wife of one interviewee, for example, *'liked the birds and wildlife'* (DEN3) and they had a large garden with nest boxes and a summerhouse where she liked to sit. Another carer interviewee (DEN4) described how her mother used to enjoy going and feeding the birds by a local loch before it became too physically demanding for her to get in the car. She was still able, however, to sit in the living room and watch the birds from there. A third interviewee described how his wife liked to hear and sense the birds in the park:

'There were birds of different types [in Regents Park] so in all she enjoys that because I think another thing is flutter of their sort of wings things like that...'

(DEN 9)

Two other carer interviewees also talked about the person with dementia they cared for enjoying watching the birds (DEN6) one having a dovecote in their garden: *'she loved the doves.'* (DEN7).

4.20 One or two people were said to enjoy gardening. DEN4's mother, for example, had a garden that had been adapted for her on account of her polio, and this meant that she was able to enjoy doing some gardening in specially raised beds. D's wife felt that he would enjoy doing some gardening in the home where he now lived *'even if it was just watering the plants'* but nobody seemed to do that with the residents of the care home.

What people enjoyed about nature and the outdoors

4.21 Several interviewees expanded on the themes from the survey about the benefits of looking at or being in nature. Although people used slightly different terms from one another, all talked about green spaces such as gardens and parks far more than any other sort of outdoor space. In the interviews, quite a few people talked about the person with dementia they cared for, enjoying going to a local park. Parks were also popular as a place that was easy to get to and had no steps to and people were often familiar with. One couple used to enjoy visiting a local stately home which had nice gardens to walk through, a lot of trees and

birds, with easier access. The interviewee himself enjoyed visiting open spaces in the city where he lived, including *'marvellous floral displays... You can sit there and take it all in.'*

4.22 Eight carers talked about the person they cared for enjoying nature in one way or another. For some people, this was looking at or simply being in nature. One interviewee, for example, said:

'She liked getting out and about with a wheelchair, the nature, just getting the sun on her face. It was as simple as that.'

(DEN1)

4.23 For other people, their carers said that they took pleasure from sitting and watching the world go by, sometimes in a park, sometimes by looking out of the window of their room. The interviewee above also talked about one of the residents in the care home where they worked, enjoying the view from his window:

'We have got one resident who...likes to sit near the big window and have his breakfast and he will just sit there and look out at the sky and the trees and the little bus that comes around the roundabout every sort of hour, and he is quite happy just to sit there.'

(DEN1)

4.24 A different picture was painted by one of the carers who described how they would occasionally accompany someone who had an audiology appointment at the nearest hospital, which was 28 miles away. They would be taken in an ambulance, from which the person could see the surrounding hills.

'For a lot of them that is a welcome respite from being inside that unit...we have a motor down the A9 towards hospital...just looking at the hills, going past the traffic, coming into P [name of town], just winding our way towards the hospital and getting out and going in the building and seeing different things, different smells, in a sense that is kind of like a de facto outing.'

4.25 The same person talked about outings on a community bus to a park that had wooden carvings of animals such as otters and wild deer, when people with dementia who could, were encouraged to look for the carvings. He encouraged one woman, who was very inward looking, to put out her hand and stroke the carvings, something she seemed to enjoy.

4.26 For most people, 'nature' was likely to be experienced in spaces near to where they lived. Those who had **gardens** all talked about how much the person with dementia enjoyed being in the garden, even if just to sit and watch the birds. One carer interviewee said that spending time in the garden, and actually doing some gardening, something that was made easier by the adjustments in their garden, was something that her mother really took pleasure in. This family lived opposite an open green space where in the summer various activities including galas and pet shows would take place. While her mother didn't take part in these, *'not being a great one for participating in village stuff directly'*, she enjoyed watching them happen. With the view from her bedroom window:

'She can literally sit in bed and watch things happening outside. She is not a morning person, she gets up makes her breakfast and goes back to bed and sits and reads the paper and watches the world go round outside the window. She quite enjoys having things to stare at.'

Outdoor music and dancing

4.27 Two people were reported as really enjoying music, both listening to music and dancing. DEN9's wife had started dancing at a Buddhist ceremony they had attended together: when he had tried to apologise, people there told him to let her enjoy it. They had enjoyed going out to live music events, where, if the music was to her taste, she would join in with the singing. He also described how he would:

'...take her to public place like the Regents Park inner circle during the summer period they used to have jazz musicians coming and M liked the jazz as well.'

(DEN9)

Being around other people

4.28 Carers were asked about the role of other people in the lives of people with dementia, when they were outdoors. One or two people had difficult experiences (see below): however, some people appreciated being around other people and this also came out from the consultation with people living with dementia. One interviewee, for example, talked about how his wife found it stimulating to be in the local park and see and hear children enjoying themselves:

'She would...appreciate the sights and the smells and sometimes some songs as well, especially she also enjoyed...children playing and all shouting about, talking about...sort of stimulation for her.'

(DEN9)

4.29 One woman with dementia, who had been in the forces, had told the interviewee that because of this she *'didn't mind being in new places and meeting new people'* (DEN2). On the other hand, being around other people could be a barrier for some people with dementia, whom it was felt by one interviewee might be overwhelmed by too much stimulation.

Water

4.30 Enjoying being near water was a theme that came out strongly from the consultation with people living with dementia. In the interviews with carers, a more mixed picture emerged. Some people said that the person they cared for enjoyed walking by a canal or lake, whilst others said that this was not true for the person with dementia they cared for, or had cared for. One interviewee, for example, explained that his wife had been pushed into a swimming pool by her brother-in-law when younger and this had made her afraid of swimming. She did, however, enjoy being beside the lake in Hyde Park:

'She enjoys the lake, the breeze across the lake things that she enjoys...yes I mean she enjoys the water in a sense not dipping into it but beside it yeah'.

(DEN9)

Nature as a memory trigger

4.31 In the consultation with people with dementia, a strong theme was that people felt that they wanted to be in the present and didn't want to go back to the past. In the interviews with carers, on the other hand, several people spoke about how the person or people they cared for would enjoy activities that reminded them of what they did in the past, or that would act as a trigger. So, for example, one person said how their father-in-law, who used to be a mountain climber, enjoyed walking even though nowadays he could only 'shuffle along':

'Once he is out walking and shuffling along, at his own pace he starts to talk, he starts to remember, he starts to engage with you... he will walk a few more paces, he will reach out and he will touch the grass or a leaf, or a flower and that will jog his memory.'

(DEN6)

Past and future

4.32 Although interest in the past was not a significant feature among people with dementia in the carer interviews, some people talked about finding ways to help their loved one remember things they enjoyed in the past. And some things that the person with dementia did now, like enjoying dancing and singing, seemed to be because they were things she had enjoyed doing when younger and before having a dementia diagnosis.

4.33 One of the interviewees reflected on her experience as a paid carer and that the person with dementia where she had worked seemed to enjoy music from their younger days. She also remembered her grandfather, from her own history, in Turkey, who had had dementia. When younger he had been a shepherd, and then when he was older he:

'used to wander and would get lost and we would find him in the field outside the village and that was because he was a shepherd in his youth and he was looking for his sheep... he loved being outdoors and just going walking but obviously he wasn't safe...he didn't know how to get back. We used to find him and say what are you doing out here and he would say I am looking for my sheep.'

This woman understood that people's pasts could be important to them. She had also worked with the people mentioned previously one of whom had been a professional runner in his youth and the other in the forces and enjoyed going to new places, both of which provided opportunities for outdoor activity to promote positive memories.

Stimulation of the senses

4.34 Several carers talked about how the person they cared for appreciated engaging with sensory aspects of nature, for example the enjoyment of seeing and smelling different things (DEN1), or touch: one woman who was 'very inward looking' enjoyed touching wooden carvings of animals. Another person living with dementia was reported as really enjoying the sensory garden in the care home where they lived, and a fifth person enjoyed the tactile surfaces in the park (DEN9).

What were the main barriers to them taking part in or enjoying outdoor spaces?

4.35 **Psychological barriers**, the symptoms of the dementia itself, such as hallucinations (DEN1) were a barrier to some people staying active or getting out into nature. On the other hand, one interviewee spoke movingly about how her husband enjoyed life more now that he had dementia, than he had before his diagnosis. He was someone who had a long-standing mental health problem that had severely curtailed his ability to enjoy life, and which had made him quite aggressive and difficult to be around (DEN5). More recently, he was said to enjoy being looked after and to spend time in the car with his wife going on outings.

4.36 **Environmental barriers** also came up in the interviews with carers. These included a lack of accessible toilets (for example, DEN5's husband) and being stuck on the top floor of a care home with nobody to take the person out into the garden (DEN8).

4.37 **Getting lost, fear of getting lost, confusion or lack of confidence** was another barrier to some people with dementia being able to go out and enjoy nature. As touched on above, B's wife was inclined to get lost if she went out on her own. She did not fear this happening, was more unaware that it was likely, hence her husband checking she was safe from his bicycle. Some people were worried about getting lost if they went out, while some people would go out but might then become confused and not be able to find their way home again.

4.38 Several people had physical limitations that restricted their ability to enjoy nature. As in other parts of the project, these were primarily around mobility. As well as DEN4's mother who used a wheelchair, one interviewee's husband couldn't get around unaided, and another interviewee's father-in-law could only manage flat ground.

4.39 Carers were asked about the role of **other peoples' attitudes** in shaping people's access to or enjoyment of nature. DEN8 said that people didn't necessarily make allowances for her husband's behaviour as there was nothing visibly wrong with him 'so they just thought he was like a rude unpleasant man.' When she explained that he had Alzheimer's, however, people were mostly apologetic.

4.40 One of the main things that people with dementia asked for was **support and encouragement**: 'someone to take me' outdoors or into nature. This was a view that was broadly echoed in the interviews, where several interviewees raised this as an issue. Several interviewees felt strongly that it was everyone's job to make sure that people with dementia had access to nature. One, for example, said that:

'I just think it is really important that people have access to [the outdoors]...often what we find is, once you get somebody outside then their whole kind of demeanour changes, they end up really enjoying it, I mean there are occasions when we have to really persuade people to go outside and then they go and they sit and they actually really enjoy it, but...especially in hospital situations...being inside for too long they get out of the habit of going outside...I just think it is important to give people the opportunity even if they don't show any interest, to still try and encourage them to try it because as I said I think a lot of people get a lot out of it.'

4.41 Interviewees tended to focus on support for people with dementia living in care homes because of their experience of paid caring roles, rather than people with dementia living at home. Interviewees talked about there being nobody available in care homes to take people out. Sometimes this was put down to a shortage of staff; at other times this was seen as a problem because staff simply had too much to do taking care of the physical care needs of residents. One carer interviewee described, for example, how:

'If you get one individual pushing the boundaries and that happens to be a person that shows aggression in dementia it will take the two carers to handle that situation safely. What happens to the rest of the place?'

4.42 Others said it was a lack of interest by staff in encouraging residents in their care home to get out, even if only into the grounds of the home to enjoy some fresh air. In one care home, while there was a small outside space, the carer interviewee felt that *'for the vast majority of people the outside isn't really a go area.'* He reflected that in many places not much attention was paid to the ease of access for people who are getting a bit frail but could still walk.

5. Summary of key findings from carers

5.1 The findings presented below are those that emerged from both the survey and the interviews.

Activities

5.2 Four out of five people agreed that regularly taking part in outdoor activities and nature is beneficial for people who are living with a dementia. According to carers, spending time just 'being' in nature was ranked as the pastime that people living with dementia took part in most frequently (38% of people living with dementia were said to do this several times a week or more often). In the interviews with carers, this was unpacked as meaning, for example, the person with dementia enjoying sitting in a car looking at the sea, or sitting on a bench in the local park watching children playing and taking pleasure from this.

5.3 Informal walking was the second most commonly cited activity. 33% of carers mentioned it as something the person with dementia did at least several times a week. Wildlife watching was also popular.

5.4 Carers reported that on the whole the people living with dementia who they cared for, would choose to take part in similar activities to the ones they already took part in, even if the right support and information were available. In other words, people were already able to participate in activities that they would choose. For example, 78% would look at or be in nature; 60% would watch wildlife; 49% would do some walking.

5.5 The major exception was community gardening or farming. When asked how often people with dementia currently take part in this, the vast majority (79%) were said to never take part in either of these. However, when asked what they would do if the right sort of support and information was available, respondents said that 28%, or almost one in three, of people with dementia would choose to participate in one of these.

Places

5.6 The most popular places to visit were public parks and gardens – 63% of carers lived less than a mile away from one of these and 46.5% said the person with dementia they cared for regularly visited one of them. However, more than half (54.5%) of carers said the person with dementia visited such spaces less than once a month. Over a quarter of people with dementia were said to visit places involving water.

5.7 Farmland and countryside were said by carers to be visited by a third of people living with dementia, at least once a month. 44% of people in the survey lived less than a mile away from farmland or countryside, which is a greater proportion than the national average where at least 60% of the population live in urban areas (Pateman 2011).

Key factors that help or hinder engagement

5.8 80% of carers agreed that regular visits to the natural environment and taking part in nature-related activities is beneficial for people who are living with dementia, provided that they have access to whatever support is needed to enable them to do this.

5.9 However, almost 65% agreed that it was difficult for people living with dementia to participate in outdoor activities. This shows that carers are aware of barriers that may block people living with dementia from taking part in outdoor activities, and most carers (76%) agreed that dementia-specialist services are needed to support people with dementia to take part in these types of activities.

5.10 Although most carers (82%) agreed or strongly agreed that it was easy for them to visit nature spaces on a regular basis 69% felt they needed support to enable the person living with dementia to visit nature spaces.

5.11 Carers identified a lack of confidence (73%), fears and safety concerns (73%) the restricted mobility of people with dementia (30 references to this in the qualitative responses in the survey), transport issues (68%), and the support of others (14 mentions in the qualitative responses in the survey) as key factors in the engagement with the outdoors and outdoor activity for people with dementia.

5.12 83% of carers agreed that the dementia did limit the person's ability to use outdoor spaces.

5.13 73% of carers agreed with the statement that it was easy for them to find information about outdoor activities and nature spaces.

6. Common themes and recommendations for action

Introduction

6.1 Although the areas for investigation were broadly the same the views of people with dementia were collected in different ways from carers and these findings have been already reported separately. An important aspect of this project, and the way it was carried out, was to capture the experiences of people with dementia in their own words, thus providing us with an invaluable insight into their relationship with the natural world. For example, the focus group discussions enable us to appreciate how someone who struggles with memory can express a preference for outdoor activities rooted in the 'here and now', while wanting to continue to be supported to do what they enjoy doing for as long as possible.

6.2 The carers who participated in the project were not known to be the carers of the people with dementia who participated and even if some were, there was no way of knowing this. Comparing the findings from people with dementia with those from carers was therefore not a straightforward comparison between like and like or the same experiences viewed through the person with dementia's eyes, and those of their carer. An analysis was done that looked across both sets and the following section draws out common themes and key findings that apply to both groups, as well as some significant differences.

Context

6.3 The following common findings provide the overarching context that has an impact on the other report findings.

6.4 As we might expect, the findings of the consultation suggest that the concept of the natural environment, of 'outdoors', is heavily influenced by where people live. Many of the people who took part in this project lived in urban areas and spoke about the problems of being able to travel far beyond their immediate neighbourhoods. For them, there may be a gap between the rural idyll portrayed in popular culture and the reality of city greenspace. For some urban dwellers, the prospect of spending time in the natural environment is alien. Other findings in the report show people took comfort from the proximity of familiar landscapes, and spoke about 'escaping' to the countryside or using nature to reminisce about their lives. An understanding of the way that people living with dementia conceptualise, experience and interact with their environments (man-made and natural) is needed if we are to find the best ways to support them to make the most of outdoors.

6.5 The Greening Dementia review showed it is not clear if people living with dementia get more out of the natural environment than anyone else, but it does report the general benefits outdoor activities have for this group – see paragraph 1.6. There are a whole range of reasons why people choose to visit greenspaces or pursue activities in natural environments – physical exercise, mental stimulation, relaxation and so on – and these reasons are unlikely to be any different for most people living with dementia. Our findings

about the impact of water in a natural environment may reflect a wider emotional response to something we sense as elemental to the human condition. However, what we do know is that people with dementia are more likely than the general population to experience barriers that limit their access to the pleasures of the natural environment.

6.6 Only 11 out of the 54 people with dementia (20%) who were spoken to cited their dementia as a barrier to using outdoor spaces, whereas 83% of carers believed that dementia limited the person's ability to use outdoor spaces. This disparity could be for a number of reasons including: different perceptions of the impact of dementia; greater determination to overcome the impact of dementia by people with dementia; greater anxiety or less confidence among carers about what a person with dementia could do; people with dementia participating in the project being less impaired than those looked after by the carers who participated. However, it should be noted that where this does represent an over-cautious view among carers (which would mirror the risk averse culture in many health and social care services) then it may inhibit the engagement with nature by people with dementia and so the provision of support and information may assist carers in overcoming some of their concerns.

6.7 In the carers' survey, over half of respondents (55%) said that the person living with dementia had other health conditions or a physical disability that limited their use of outdoors spaces and nature – this correlates with evidence from elsewhere about co-morbidities and dementia.

Common themes

6.8 The findings below (paragraphs 6.9-6.15) are the key findings emerging from information-gathering with both people living with dementia and their carers: that is, the themes were relevant to both groups of people. Where the significance of the theme varies across the groups, this is spelled out.

6.9 Informal walking was the most commonly cited activity by people living with dementia and carers. Informal walking was mentioned by 38% of people with dementia and 33% of carers mentioned informal walking as something the person they cared for did at least several times a week. What walking meant to the person living with dementia came up strongly during interviews with carers, several of whom talked about the calming effect that this had on the person they cared for. This was vitally important to some as an escape from the pressures of being indoors, and could be as important to the carer as to the person with dementia.

6.10 Wildlife watching, usually bird watching, is very popular amongst people living with dementia. In the survey 25% of people were said to take part in it several times a week or every day. 25% of people living with dementia had an interest in encounters with wildlife, one specifically with birds of prey. In the interviews with carers, six of the ten people interviewed talked about the person they cared for enjoying spending time watching – and sometimes listening to – the birds.

6.11 Places associated with water (inland, coast, natural, artificial) were the most popular places among people with dementia (45%) and in the carers' survey, over 25% of people living with dementia were said to visit places involving water; either rivers, canals and

waterways, or seaside, beach and coastal areas, at least once a month. It should be noted that people living with dementia were asked about places they liked to visit, whereas carers were asked to state the frequency with which the person they cared for visited such places).

6.12 In interviews with carers, several interviewees talked about the person they cared for enjoying time by water. Lakes in particular were places that were talked about positively as being environments where the person living with dementia and their carer could relax. For others, however, proximity to water could instill fear due to bad memories. Thus the picture that emerged overall from carers was far less positive than that coming from people living with dementia. This disparity may exist for similar reasons to those discussed in the section on 'Context' above, regarding the impact of dementia on people's activity outdoors.

6.13 People with dementia talked about the importance of engaging in outdoor activities that have a purpose and/or that involve being with other people. Several mentioned an interest in working an allotment either in the present or in the past, yet the carers survey suggests that urban greenspaces where such outdoor activities might be pursued - allotments, urban farms, churchyards and cemeteries – are rarely frequented by the people they support.

6.14 City parks or public gardens were one of the most popular places that people with dementia visited. About 30 % of people with dementia talked about visiting city parks and gardens. 46% of carers said the person with dementia visited one or the other at least once a month and almost two thirds (63%) of the survey respondents (carers) said they lived less than one mile away from a park or public garden. Several people with dementia consulted talked passionately about the role their local park played in providing them with somewhere to go, and as somewhere to enjoy watching other people taking part in activities.

6.15 Transport and mobility were the outstanding common factors for both people with dementia and carers; availability, the support of others ('someone to take me'), and personal attributes (limited physical mobility) were key factors in helping or hindering engagement with nature.

Recommendations for action

6.16 Many people with dementia can enjoy the natural environment given the right support (and information). Even people with dementia who have restricted mobility can enjoy time in nature, especially if accompanied or supported by someone who knows (and understands) them. People in the later stages of dementia, including those with no verbal communication, can still enjoy the natural environment, especially parks or listening to the birds and music outdoors, or slightly more ambitious activities such as community gardening or farming.

6.17 The report identified a number of factors that could help or hinder people with dementia engaging with the outdoors and outdoor activity. However, in terms of regular engagement with the outdoors and outdoor activity the evidence from the report indicated that staying local and close to home, the presence of water, walking and wildlife watching are the aspects which are likely to appeal to most people.

6.18 The consultation generated a good deal of information about the places where people with dementia living in their own homes interact with nature and the activities that

they engage in at those locations. The survey found that many local spaces are underused by people with dementia. The reasons for this were not always clear, although factors such as perceived danger were highlighted, but a simple lack of awareness and information about what those spaces have to offer may have contributed as well.

Recommendation 1 - Development of local directories of dementia-friendly open spaces and facilities, perhaps using a 'trip-advisor' approach or by conducting an audit, could encourage greater use of natural spaces by people living with dementia. Managers of natural environments and organisations providing activities in outdoor spaces should be encouraged to develop and follow the principles of dementia-friendly communities. Local dementia action alliances (DAAs), where they exist, potentially offer good cross-sector opportunities to undertake this type of work.

6.19 The findings of the consultation suggest strongly that activities are the main motivating factor for engaging people with dementia with the natural environment. The project found that people living with dementia were motivated to take part in social activities such as guided walks and listening to the birds and music in outdoors spaces, and enjoyed informal walking as an activity in itself and as a means of calming down and relaxing, but also slightly more ambitious activities such as community gardening or farming.

Recommendation 2: Organisations planning or providing activities for people living with dementia need to take account of the importance of social activities as a key factor in stimulating engagement. Local services responsible for outdoor public spaces should consult with relevant groups and individuals with dementia (through local DAAs, where they exist) to gain an understanding of how best to ensure the inclusion of people with dementia in the activities they provide.

6.20 However, place was also important and clear views were expressed about the preference for people living with dementia and carers visiting locations with access to water (inland, coast, natural or artificial), closely followed by public parks and gardens. The strength of this association appears to combine an emotional concept of nature (positive, soothing, aesthetic qualities associated with water) with the practical reality of many people's day to day engagement with nature which may be limited by geographical location or factors such as transportation, support, physical mobility, or the impact of dementia.

Recommendation 3: Organisations planning and providing activities for people living with dementia should take into account the type of place that motivates people living with dementia to be engaged.

6.21 Significant barriers to participation by people living with dementia were a lack of transport and inadequate support both to get to locations, to use facilities and to participate in outdoor activities.

Recommendation 4: Collaborative working between organisations providing services to people with dementia, organisations managing outdoor spaces, local transport organisations and through local dementia action alliances, for example, could generate innovative partnerships and solutions to enable people with dementia to access public spaces outdoors.

6.22 Linking this activity with the movement towards ‘dementia friendly communities’ and the work of local DAAs, increases the potential for positive engagement, impact and sustainability. All of these could significantly enhance the potential for people living with dementia to feel part of the community and to enjoy their local nature spaces.

6.23 Carers tend to be more cautious than people with dementia about what the latter can do outdoors and have concerns about issues such as safety when in natural environments.

Recommendation 5: Carers’ organisations and the providers of support to people with dementia have a role to play in encouraging family carers and paid staff to be more ambitious in their expectations of what people with dementia can do. This could be achieved through the sharing of innovative good practice highlighting the positive outcomes, and how concerns and practical difficulties have been overcome to enable someone living with dementia to participate in outdoor activities safely.

6.24 The findings of the consultation allied to previous research evidence indicates that people with dementia often suffer multiple disadvantages in accessing and using structured environments such as parks. Problems with mobility, tiredness and disorientation can have a significant impact on the ability of people living with dementia to enjoy them. In particular, the availability of accessible signage, toilets and cafes, places to sit and relax located in spots with even ground that are easy to find, and the presence of someone trained in dementia awareness to offer support and information.

Recommendation 6: Organisations designing and managing outdoor spaces should ensure the availability of accessible signage, facilities such toilets, cafes, places to sit and relax which are easy to find, walkways located on even ground, and the presence of someone trained in dementia awareness to offer support and information.

Recommendation 7: Greenspace managers should fulfil their obligations under equalities legislation to make reasonable adjustments and to consider the specific needs of people with dementia. They should form local alliances with groups and individuals with experience of dementia, or join existing ones (such as local dementia action alliances) to assist in planning, training and quality assurance in the delivery of services.

6.25 Some providers of managed outdoor environments may already be working towards this and some may be aspiring to make these changes but don’t know how to implement them. Undertaking dementia-accessible audits involving people with dementia, providing ‘dementia friends’ awareness sessions, offering more specialist training and becoming part of a local dementia action alliance (where one exists) are some of the ways in which these change processes can be put into effect.

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Appendix 1 – Online survey for carers

Dementia and Engagement with Nature

Is it nice outside?—Consulting people living with dementia and carers about outdoor activity and nature

The Mental Health Foundation is carrying out a research project, commissioned by Dementia Adventure and Natural England, to explore the role of outdoor activity and nature in enabling people to live well with a dementia. The Dementia Engagement with Nature (DEN) project is also interested in the views of people who are supporting or caring for a person who is living with a dementia.

We would like to know your views about the types of outdoor activities and nature spaces that people living with dementia use and enjoy. We are interested in understanding why people with dementia do or don't participate in outdoor activities and nature, as well as how to make nature spaces more dementia friendly. The information gathered in this survey will be presented in a project report in July 2015 which will contribute to scoping projects that support access to natural outdoor spaces and outdoor activities for people who are living with dementia

Innovations in Dementia CIC, is working in partnership with the Mental Health Foundation to carry out this research. They will be carrying out focus groups with people who are living with dementia to seek their views about the role of nature spaces in living well with a dementia.

Terminology: In this survey we use the term 'living with dementia' to mean someone who has been diagnosed with a type of dementia.

Nature refers to any public space within a natural environment including:

- Parks and public gardens
- Community allotments and city/urban farms
- Cemeteries and churchyards
- Woodlands, forests and national parks
- Rivers, canals and waterways
- Farmland and countryside
- Moorlands and mountains
- Seaside, beach and coastal areas

In this survey, nature does not include private/home gardens.

Consent and confidentiality: The information gathered in this survey will be stored confidentially and will only be accessible to the project team. Any information that is used in the final research report will be anonymised and non-identifiable. You may choose to withdraw your participation in this research at any time. Please contact Katrina Jenkins (KJenkins@mentalhealth.org.uk or 0207 803 1130) for any queries or for more information about this project.

If you agree to take part in the Dementia and Engagement with Nature survey, please click 'next'.

About you - Background information

1. Please indicate which of the following most closely describes the area where you live:
 - a. Inner city/urban
 - b. Suburbs
 - c. Town
 - d. Village
 - e. Rural
 - f. Other (please specify)
2. Please indicate where you live:
 - a. England
 - b. Northern Ireland
 - c. Scotland
 - d. Wales
3. Please indicate your gender
 - a. Female
 - b. Male
 - c. Prefer not to say
 - d. Other (please specify)
4. Please tell us your age in years
5. Please indicate your ethnic/cultural background.
 - a. English
 - b. Irish
 - c. Scottish
 - d. Welsh
 - e. Caribbean/British Caribbean
 - f. African/British African
 - g. Indian/British Indian
 - h. Pakistani/British Pakistani
 - i. Chinese/British Chinese
 - j. Arab/British Arab

- k. Other Asian background
- l. Other African background
- m. Other European background
- n. Other mixed background
- o. Prefer not to say
- p. Other (please specify)

About you – visiting nature spaces

6. Please estimate the distance from your home to the nearest of each of the following nature spaces:

Scale: *Less than 1 minute walking distance; approximately 1 mile away; 1-5 miles away; 5-10 miles away; more than 10 miles away; don't know*

- a. Parks and public gardens
 - b. Allotments and city/urban farms
 - c. Cemeteries and churchyards
 - d. Woodlands, forests and national parks
 - e. Rivers, canals and waterways
 - f. Farmland and countryside
 - g. Moorlands and mountains
 - h. Seaside, beach and coastal areas
 - i. Other (please specify)
7. Do you have any health conditions or a physical disability which limits your ability to visit nature spaces?
- a. Yes
 - b. No

8. Please rate the extent to which you agree or disagree with the following statements:

Scale: *Strongly agree, Agree, Neither, Disagree, Strongly disagree*

- a. It is easy for me to visit nature spaces on a regular basis.
- b. As a family carer, I need support to enable the person living with dementia to visit nature spaces.
- c. It is easy for me to find information about outdoor activities and nature spaces.

Living with dementia and taking part in nature

This next part of the survey is about the person (or people) you support who are living with a dementia.

9. Please describe your relationship to the person with a diagnosis of dementia (e.g. spouse, daughter, sibling, friend, etc.).

10. Approximately how long has the person been living with dementia (e.g. since symptoms were first noticed, or since receiving a diagnosis)

- a. Less than 1 year
- b. 1-5 years
- c. 5-10 years
- d. More than 10 years
- e. No diagnosis yet received
- f. I don't know

11. Please indicate the type of dementia that was diagnosed.

- a. Alzheimer's disease
- b. Vascular dementia
- c. Lewy Body dementia
- d. Fronto-temporal dementia
- e. Mixed dementia
- f. I don't know
- g. No diagnosis received
- h. Other (please specify)

12. Has the dementia limited the person's ability to use outdoor spaces?

- a. Yes
- b. No

13. Please briefly describe how the dementia has affected the person's ability to use nature spaces.

14. Does the person living with dementia have any other health conditions or a physical disability which limits their use of outdoor spaces and nature?

- a. Yes
- b. No
- c. If yes, please describe:

Nature spaces

15. Please rate how frequently the person living with dementia usually visits the following nature spaces:

Scale: *Everyday; Several times a week; Once a week; 1-2 times a month; Less than once a month; Never*

- a. Parks and public gardens
- b. Allotments and city/urban farms
- c. Cemeteries and churchyards
- d. Woodlands, forests and national parks
- e. Rivers, canals and waterways
- f. Farmland and countryside
- g. Moorlands and mountains

- h. Seaside, beach and coastal areas
- i. Other (please specify)

16. If the right support and information was available, which nature spaces do you think the person living with dementia would most like to visit on a regular basis? (Please tick up to three nature spaces).

- a. Parks and public gardens
- b. Allotments and city/urban farms
- c. Cemeteries and churchyards
- d. Woodlands, forests and national parks
- e. Rivers, canals and waterways
- f. Farmland and countryside
- g. Moorlands and mountains
- h. Seaside, beach and coastal areas
- i. Any others? (please specify)

Activities and being outdoors

17. How often does the person living with dementia usually participate in the following outdoor activities?

Scale: *Everyday; Several times a week; Once a week; 1-2 times a month; Less than once a month; Never*

- a. Looking at/being in nature
- b. Exercising pets/animals (e.g. walking the dog)
- c. Wildlife watching
- d. Community gardening/farming
- e. Informal games or sports
- f. Repetitive movement/exercise (e.g. yoga, tai chi, aerobics)
- g. Walking
- h. Rambling/hiking
- i. Running/Jogging
- j. Horse riding
- k. Cycling
- l. Fishing
- m. Other (please specify)

18. If the right support and information was available, which activities do you think the person with dementia would choose to participate in? (Please tick three nature spaces).

- a. Looking at/being in nature
- b. Exercising pets/animals (e.g. walking the dog)
- c. Wildlife watching
- d. Community gardening/farming
- e. Informal games or sports
- f. Repetitive movement/exercise (e.g. yoga, tai chi, aerobics)

- g. Walking
- h. Rambling/hiking
- i. Running/Jogging
- j. Horse riding
- k. Cycling
- l. Fishing
- m. Any others? (please specify)

19. Please describe the types of support and information that would enable the person living with dementia to participate in these activities.

20. Please rate the extent to which you agree or disagree that the following items are existing barriers to you and the person living with dementia participating in outdoor activities and nature.

Scale: *Strongly agree, Agree, Neither, Disagree, Strongly disagree*

- a. Not enough information
- b. Fears and safety concerns
- c. Lack of spare time
- d. Nature spaces not being accessible
- e. Expense
- f. Lack of confidence
- g. Transportation
- h. Any other barriers (please describe)

21. Please rate the extent to which you agree or disagree with the following statements.

Scale: *Strongly agree, Agree, Neither, Disagree, Strongly disagree*

- a. Regularly taking part in outdoor activities and nature is beneficial for people who are living with dementia.
- b. It is easy for people living with dementia to access support and information about participating in outdoor activities and nature.
- c. It is difficult for people living with dementia to participate in outdoor activities and enjoy nature spaces.
- d. People who have a dementia would prefer to participate in organised, group activities in nature.
- e. Dementia-specialist services are needed to support people with dementia to take part in outdoor activities and nature.

22. Please rate the extent to which you agree or disagree that the following adaptations will make nature spaces more dementia friendly.

Scale: *Strongly agree, Agree, Neither, Disagree, Strongly disagree*

- a. Providing accessible facilities (café, toilets, seating)
- b. Offering more information about nature spaces and activities.
- c. Having clearer signage and more maps.

- d. Having trained staff and volunteers who understand how to support people living with dementia.
- e. Creating dementia-specific meeting points.
- f. Making assistive technology available (e.g. GPS tracking devices; mobility cars)

23. Are there any other adaptations you would suggest for making nature spaces more dementia friendly?

Appendix 2 – Topic guide for interviews with carers

Thank you for agreeing to take part in this interview. It shouldn't take more than half an hour of your time. We are interested in finding out about the experiences of people living with dementia and their carers as they relate to nature and outdoor spaces. Some people with dementia have said they think of this as being the great outdoors. I am going to ask you a few questions about the person or people with dementia that you care for, and about yourself. Anything you tell me is in confidence and will be anonymised before it is included in the report. The interview will be tape recorded – just one other person will listen to this.

1. Firstly, can you tell me what sort of outdoor spaces there are near to where the person or people you care for live?

Do they visit these spaces? What do they enjoy about this / what makes it difficult or easier for them?

2. Does the person you care for sometimes go for a walk? What do you think it is that they enjoy about going for a walk?

Does the person you care for ever take part in guided walks? What do they enjoy about this / what makes it difficult or easier for them?

3. Does the person you care for ever take part in social or communal events such as listening to music at a bandstand, or other similar activities?

If they do, what do they enjoy about this / what makes it difficult or easier for them?

4. What, if anything, do you think limits their use or enjoyment of the great outdoors? (e.g. facilities / other people's attitudes / access to spaces)

5. Is some sort of water – like a lake or canal or river – the sort of place the person you care for visits?

If so, what do they do when they get there?

What do you think it is that they enjoy about this / what makes it difficult or easier for them?

6. Are there any community gardens near to where the person or people you care for live? Do they ever do any gardening there?

Do they need any support or information to do this? Do they have any support to do this?

7. Do you yourself like to visit the great outdoors, or take part in outdoor activities? Do you have any health conditions or disabilities that limit your ability to do this? If so, can you tell me a little more about what these are?

Does the person you care for have any health conditions or disabilities that limit their ability to enjoy the outdoors? If so, can you tell me a little more about what these are?

8. Other people in our survey said that the person with dementia they cared for most enjoyed walking; watching wildlife; walking the dog; or just being in nature. Thinking about the person or people you care for, what would you say they most enjoy in the outdoors?
9. Finally, is there anything you would like to add about how the person or people with dementia that you support relate to the outdoors and nature?

Thank you for your time.