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To help heritage sites get started on becoming dementia-friendly organisations, this guide contains information about how dementia affects people's experience of interacting with heritage. It also provides tips, guidance and signposting to help heritage sites become more dementia-friendly.

#### **Title**

Rethinking heritage: A guide to help make your site more dementia-friendly

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#### Rethinking heritage

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#### **Authors**

Kim Klug, Professor Stephen Page, Dr Joanne Connell, Daisy Robson, Emma Bould

#### Contact

#### **Historic Royal Palaces**

Learning & Engagement at Learning.info@hrp.org.uk

#### **Alzheimer's Society**

Programme Partnerships team at programmepartnerships@alzheimers.org.uk

#### Web

www.hrp.org.uk/about-us/learning/ alzheimers.org.uk/dementiafriendlycommunities

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### **Contents**

#### Foreword

Jeremy Hughes, Chief Executive, Alzheimer's Society	6
Sir Tony Robinson, Alzheimer's Society Ambassador	7
Liz Ellis, Policy Adviser, Communities and Diversity, Heritage Lottery Fund	9
Introduction	10
1. What is dementia?	15
2. How could dementia affect someone's visit to your heritage venue?	17
3. Making the case for dementia-friendly heritage	19
4. Creating a dementia-friendly visitor experience	24
5. Partnerships: working together to make dementia-friendly heritage	32
6. Programming for people living with dementia and carers	38
7. Overcoming obstacles: common challenges and advice from the heritage sector	48
8. Taking action: get started today!	54
9. Useful resources and organisations	56
References	58

#### Foreword (Alzheimer's Society)

Dementia is one the greatest challenges we face in society today. People affected by dementia often have to give up the things they want or need to do due to inaccessible and unsupportive environments. From stately homes to ruins, castles to outdoor museums, the entire heritage sector has a crucial role to play in tackling the social and economic impact of dementia.

For many people, heritage sites are incredibly important and a constant feature throughout our lifetime. This often ranges from visiting places of historical interest with our parents as a child or on a school trip, to going to places of national interest on holiday, or learning about different periods of history and the life of previous generations. Heritage is about beautiful historical sites and objects as well as reminiscing about different times. The importance of heritage sites increases as we get older, as a place to relax, recover and engage through multi-sensory stimulation of the environment around us.

The Prime Minister's challenge on dementia states that by 2020 the UK will be the first dementia-friendly nation. Dementia will affect everyone within every sector and across all industries, from customers to employees. Becoming a dementia-friendly organisation means providing the opportunities to support every person with dementia through greater awareness and understanding.

By developing an understanding of dementia, heritage sites can make a huge difference to people living with dementia to continue to play an active part in their communities and continue to do the things they want to do. I am delighted the heritage sector has come together to create this guide and the incredibly important work they are doing.

Jeremy Hughes

Chief Executive, Alzheimer's Society

#### Foreword (Alzheimer's Society)

It's extraordinary that dementia casts its net so wide. It means that nobody is immune, nobody can necessarily escape and we will all be affected by it in some way or another during our lifetime.

People with dementia often stop doing the things they love, not because they want to but because they don't feel supported or that they're able to access the places they want to go.

The attitude towards people with dementia can sometimes be: 'Oh, there's nothing you can do about that, it's just a natural part of growing old'. But it isn't, it's a disease of the brain and one that we need to tackle together.

If you look beyond the diagnosis, you'll find inquisitive minds that could be brought to life with the right strategies. That's why this guide is so important.

Britain is steeped in history and remarkable places of natural beauty. We all enjoy stepping back in time and following in the footsteps of Roman soldiers or relaxing in the gardens of a majestic country house.

Visiting heritage sites is one of the most popular activities that people with dementia want to continue doing. Heritage sites can play a crucial role in supporting people with dementia to enjoy a connection with the places they love and help to improve their well-being.

By 2020 the UK aims to be the first dementia-friendly nation, transforming how every sector and industry thinks, talks and acts about the condition. Providing opportunities to support every person with dementia, through greater awareness and understanding, will not only help organisations become dementia-friendly, it'll be part of a movement to transform the landscape of dementia forever.

Defeating dementia won't happen overnight. We will find a cure, but until that day we must all pull together if we're to create a dementia-friendly society.

Have things got better? Yes, but we've got Everest to climb and we're only at base camp. The whole of society has a role to play.

We need to make a commitment to people affected by dementia so they can enjoy the honourable life they deserve without fear, prejudice or isolation.

Both of my parents died with dementia, so I know from personal experience the impact this condition has on everyone touched by it and how important it is to know that support is out there when you need it.

That's why I'm proud to support this guide and commend the heritage sector for coming together in this way to support people living with and affected by dementia.

Sir Tony Robinson

Alzheimer's Society Ambassador



#### Foreword (Heritage Lottery Fund)

Enjoyable activities, feeling welcome at heritage sites, having fun, meeting new people during a trip to a beautiful place. Sounds great, doesn't it?

Whilst most of us expect these opportunities to be available for children as part of formal or informal learning, growing evidence<sup>1</sup> shows that having access to high quality cultural activities is important for all age groups, especially people with ill health such as dementia<sup>2</sup>.



You may already be aware of imaginative, co-produced heritage projects involving people living with dementia, carers, friends and family taking place across the UK. These inspiring partnerships in parks, museums and many other visitor attractions, both outside and indoors, all promote enjoyable, active learning and also improve our sense of connectedness with each other.

But what are the aims of these projects? What are the challenges? How can we learn with each other, including people living with dementia to make active partnerships sustainable and truly participatory? What does success look like and how can we demonstrate this success?

This resource is the result of the generous sharing of expertise in making heritage sites more dementia-friendly. Contributions have been made by both individuals and organisations, underpinned by the recognition of inclusion as an active process yet to be perfected. The resource is a result of meetings in 2016-17 by heritage professionals and allies at the Alzheimer's Society, Scouts Association and many others. Everyone involved in producing this resource recognises the challenges as well as opportunities in effective partnership working - and the finite limits of local and national funding contexts.

As a funder, the Heritage Lottery Fund (HLF) is proud to have inclusion as an organisational priority and is active in building inclusive heritage ambition, both within HLF and with our grantees<sup>3</sup>. We recognise the process of achieving inclusive heritage where people living with dementia are welcomed, is not only based on funding but relies on senior, strategic commitment from heritage organisations. We know that participatory heritage projects also require support and knowledge from health charities, local Dementia Friends networks, local businesses and other partners to embed sustainable best practice for everyone.

This resource is ambitious but also realistic. All contributors recognise that for dementia friendly heritage sites to develop, an active dialogue is required. The benefits to be had from connecting with each other through enjoyable, sociable activities in amazing heritage places have never been clearer!

Liz Ellis

Policy Adviser Communities and Diversity Heritage Lottery Fund. Heritage Lottery Fund uses National Lottery players' money to fund a wide range of activities benefitting heritage, people and communities across the UK.

<sup>1.</sup> Understanding the value of arts and culture AHRC Cultural Value chapter 7 Health ageing and wellbeing p100-112

<sup>2.</sup> www.artshealthandwellbeing.org.uk/appg/inquiry

<sup>3.</sup> www.hlf.org.uk/community/general-discussions/how-can-we-make-heritage-inclusive-everyone



People living with dementia are a significant and growing population in the UK and worldwide. Currently, there is an estimated 850,000 people living with dementia in the UK. This number is expected to rise to over 1 million people by 2025 and 2 million people by 2051. Older audiences – a core visitor group for the heritage sector – are more likely to, but not exclusively, experience dementia. As a result, heritage sites should expect to feel the impact of dementia on their business as the population grows in the coming decades.

The impact of dementia on heritage sites remains largely under-researched,<sup>2</sup> but it is anticipated that, as their condition progresses, individuals living with dementia will require more support to visit heritage sites. The Prime Minister's Challenge on Dementia was launched to make the UK the first dementia-friendly nation by 2020. The aim is to support people with dementia to live well in their community and enable them to continue doing the everyday things that we all take for granted, such as visiting a local heritage attraction. This guide was created to support this ambition. It was written by a collection of heritage professionals who recognise with an ageing population this will affect visitors, volunteers and staff and are working to define what dementia-friendly heritage looks like for their organisation.





### The scale of the challenge<sup>3</sup>





over the age of 80 have dementia



will develop dementia this year, that's one every three minutes



younger people (under the age of 65) live with dementia



with dementia live in the community; a third live in care homes



There are 670,000 carers of people with dementia

# Dementia

is the leading cause of death in England and Wales (ONS, 2016)



#### The guide

The guide aims to be a 'call to action' for the heritage sector and to inspire more organisations to work towards becoming dementia-friendly by making the sites and programming content more accessible for people living with dementia and their carers. It is aimed at individuals working or volunteering at heritage sites who are in a position to implement dementia-friendly changes in both policy and practice in their organisation.

#### This guide aims to:

- Promote awareness and understanding of dementia
- Explore the impact of dementia on the heritage sector
- Outline a business case for dementia-friendly heritage
- Offer practical guidance for making a heritage site dementia-friendly

It is important to recognise that the heritage<sup>4</sup> sector is incredibly diverse and there is no 'one size fits all' approach to being dementia-friendly – it will look different from site to site. Heritage sites have wide-ranging and unique challenges including limited resources (for example, staffing or budgets), physical access and conservation constraints, to name a few! The guide aims to inspire more dementia-friendly practices, and offer support and encouragement. It is unrealistic that all the 'top tips' will be practical for every heritage site to implement. Readers are experts on their sites and are encouraged to tailor this best practice to their site in order to define what dementia-friendly looks like for your organisation. It is important to remember that small changes can make a big difference to people living with dementia.

Dementia-friendly heritage is a developing field of work which we hope will change and improve over time. We acknowledge that this resource will need to be reviewed and updated to reflect feedback from the sector and provide new examples of best practice.

This guide is inspired by Alzheimer's Society's 'Becoming a dementia-friendly arts venue: A practical guide' (2015) which is part of their 'Dementia Friendly Communities' programme linked to the Prime Minister's Challenge on Dementia.

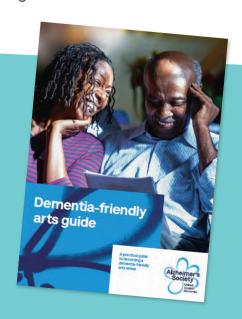


#### Find out more:

'Becoming a dementia-friendly arts venue: A practical guide': alzheimers.org.uk/download/downloads/id/2838/becoming\_a\_dementia friendly\_arts\_venue\_a\_practical\_guide.pdf

'Dementia Friendly Communities' programme: alzheimers.org.uk/DementiaFriendlyCommunities

'Prime Minister's Challenge On Dementia 2020': www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/prime-ministers-challenge-on-dementia-2020





#### 1. What is dementia?

Dementia is not a natural part of the ageing process. It is caused by diseases of the brain and it is progressive. This means it begins with mild symptoms that get worse over time. There are over 100 different types of dementia but the most common are including Alzheimer's disease and vascular dementia, which can be caused by strokes. Different types of dementia tend to affect people in different ways, especially in the early stages.

Dementia affects people in different ways, depending on the condition as well as the person.

#### A person with dementia might:5

#### Have problems with day-to-day memory, for example:

- have problems recalling things that happened recently (although some people easily remember things from a long time ago)
- · forget their birthday, address or PIN
- repeat themselves or continually ask the same question.

## Have difficulty making decisions, solving problems or carrying out a sequence of task, for example:

- have problems concentrating, following a series of steps, grasping new ideas or solving problems
- struggle with familiar daily tasks, such as following a recipe or using a debit or credit card.

#### Have language or communication problems, for example:

- have difficulty finding the right word
- struggle to follow a conversation or misinterpret things.

#### Being confused about time or place, for example:

- lose track of what time, date or season
- not know where they are, even in a place they are familiar with.

#### Have problems with sight, visual perception or visual hallucinations, for example:

- have difficulty judging distances (for example, on stairs)
- · see objects in three dimensions or see things that are not really there
- misinterpret patterns or reflections in mirrors and perceive them as something else.

#### Show changes in their mood or difficulties controlling emotions, for example:

- become unusually sad, frightened, angry or easily upset
- lose interest in things and become irritable, frustrated or withdrawn
- become anxious or lack self-confidence

#### Show changes in behaviour, for example:

• questioning, pacing, restless or agitation

#### Living well with dementia

A diagnosis of dementia does not mean it is not possible to live well. Many people with dementia continue to drive, socialise and work. Even as dementia progresses, people can lead active, healthy lives, carry on with their hobbies and enjoy friendships and relationships. Someone with dementia may forget an appointment or tell you the same joke twice, but their condition does not stop them doing the things that matter most.

The most common issues are:6

**69%** 

a lack of confidence

68%

being worried about becoming confused

60%

being worried about getting lost

59% mobility issues

**59%** 

physical health issues

44%

not wanting to be a burden to others

33%

lack of appropriate transport

# 2. How could dementia affect someone's visit to your heritage site?

The effects of dementia differ from person to person, but someone with the condition might experience:

#### Problems with mobility and navigating around the heritage site, for example:

- · find it difficult to get to the venue
- struggle with unclear signage
- · find patterns or shiny surfaces disorientating
- · be overwhelmed by background noise
- fear of getting lost inside a site; have problems finding toilets or exits
- fear of not knowing where to go or who to go to for additional support
- worry other visitors, staff and volunteers will react negatively if they do not follow social cues.

#### Challenges caused by their memory problems, for example:

- struggle to remember a different time or era, follow complex interpretations, read maps, guidebooks, exhibition text or leaflets
- unable to find the right words to describe what they need or want.

#### Difficulties with their visual perception and spatial awareness, for example:

- bump into objects or barriers
- have perception issues, which may be heightened due to low light levels or shadows
- respond to interpretation, such as projections and soundscapes, in unexpected ways.

#### Problems with paying, for example:

- have difficulty remembering chip and PIN codes
- have trouble counting or recognising money, coping with payment methods
- feel rushed or worried that they will forget how to pay or actually forget to pay.

#### Impaired sensed or reduced ability to interact with their environments:

• people with dementia might find it easier to interact with the site using their senses: looking at visual art, handling objects, listening to music.

In addition, people may have other health issues alongside dementia - such as hearing loss or mobility problems - that could affect their ability to get around your venue or appreciate what is on offer.



### 3. Making the case for dementia-friendly heritage

#### Dementia: why it matters to the heritage sector

Dementia changes lives. Loss of memory, struggles with communication and language and changes in behaviour can have a negative impact on a person's core sense of self. This disease changes relationships with people, places and things, and, potentially, can lead people living with dementia and their carers to become isolated.<sup>7</sup> Often, people with dementia stop participating in activities they previously enjoyed. These can include exploring, discovering and connecting with heritage, which is an experience that plays an 'important part in how people view the places they live, how they feel and their quality of life.'8



Olive and Yvonne with the Military Patchwork Quilt, Compton Verney Art Gallery and Park

As health and wellbeing are increasingly recognised as societal issues<sup>9</sup> in which heritage can positively impact,<sup>10</sup> it is timely to consider the top health and wellbeing concerns facing the sector. Dementia is a condition that is likely to, though not exclusively, affect older audiences, who are a traditional and core visitor demographic for the sector.<sup>11</sup> As dementia is often a hidden disease, it is likely there are already people living with and affected by dementia represented in our visitor audiences, volunteer teams and staff.

Dementia-friendly heritage is not just about 'being nice', it is good business practice: ethically, financially and legally. It is about being accessible, inclusive and relevant to our existing and potential audiences.

#### The ethical case: Heritage can help people 'live well with dementia'12

People living with dementia can live well for many years after diagnosis and, with appropriate support, can continue to engage and contribute to society and have a good quality of life.<sup>13</sup> Mental, social and physical stimulation has been shown to help reduce behavioural symptoms of dementia, such as apathy, agitation and dependence; as well as improve mood and reduce anxiety.<sup>14</sup>

#### The social benefits of becoming dementia-friendly are as follows:

- · Helping people to live well with dementia
- Helping people stay independent
- · Improving accessibility for the whole community
- Reducing social isolation.

## In comparison to other visitor attractions, people living with dementia view heritage sites as 'safe' and familiar spaces. The key attributes they want from a day out are:

- an attractive day out: historic buildings, collections, parks or gardens
- a relaxed and uncrowded environment
- being looked after in a secure environment with clear boundaries and manned entrance/exit points
- provision of a café and good access to toilets
- places that prompt memories of the past.

# 'Visiting [heritage sites] brings back memories and makes you think about your family.'

Person living with dementia, member of The Unique's (Service User Review Panel, Gwent)

This is particularly important as dementia progresses. Visiting heritage sites is already associated with positive life satisfaction and wellbeing, 16 but for people with dementia and carers, sites can offer the vital social connection to the world around them. Historic spaces, collections and stories can prompt and stimulate discussion and connection, encourage outdoor exploration and provide spaces for relaxation 17 all which enable engagement and continued contribution to society.

'Gas masks hanging in the house at Avoncroft Museum [reminded me of] practices at my school. We were all encouraged to knit at an early age and we knitted squares to make scarves for the sailors. During a gas mask practice we were told to continue knitting but my mask was steaming up, so I just clicked my needles together and the teacher didn't realise I wasn't knitting!'

Person living with dementia, member of Bromsgrove Service User Review Panel

#### The financial case: Dementia-friendly heritage is good for business

With more leisure time and higher levels of disposable income, the over 65s are a significant contributor to the UK's visitor economy, generating 20% of the industry's income.<sup>18</sup> There are significant risks to not taking action, particularly around staff

retention and neglecting the needs of visitors, which can result in lost revenue. This is significant to the heritage sector, especially considering a recent study on dementia-friendly tourism which noted that day trips are the mostly likely and most regular leisure activity for people living with dementia and their carers.<sup>19</sup> For heritage, this can translate into ticket sales, retail and hospitality spend, boosting economic growth whilst building stronger and healthier communities – all of which are supported by the Department of Culture, Media & Sport.<sup>20</sup>

#### **The Dementia Pound**

People with dementia and their families often have considerable disposable income and spending power, with the average household affected by dementia spending £16,800 per year. The 'dementia pound' in England was worth £11bn in 2014, equating to 1.8% of household spending in England with the figure expected to double to £23bn by 2020 (CEBR). As people develop dementia they will do and spend less, unless businesses adapt to their needs.<sup>21</sup>



Museum in the Park, Stroud

'Once I've been and if I've enjoyed it, then we come again and I then bring my children and grandchildren with me.'

Person with dementia, Chichester Service User Review Panel

Dementia-friendly heritage has the opportunity to retain and generate new visitors and income. The more accessible the visitor experience is for people living with dementia, the more likely heritage sites will be able to retain existing visitors, reach

new audiences and reconnect with those who stopped visiting due to their condition. This may extend to the support system around the person with dementia: family, friends, and care providers. When a business gets it right for people with dementia, it gets it right for everyone. There is also the opportunity to generate visitor numbers during off-peak seasons, as visiting in quieter, less crowded times were sought after by some people with dementia and their carers.<sup>22</sup>

### The legal case: It is a legal responsibility for heritage to be dementia-friendly

Heritage sites are both cultural caretakers and employers, which means that they have a legal responsibility to be dementia-friendly for the general public who visit as well as their employees and volunteers.

'Heritage serves as the bridge between generations and peoples.'<sup>23</sup> Inclusion is not an option for the heritage sector, it is a legal responsibility. The right to access and enjoy cultural heritage is a human right<sup>24</sup> which is supported by UNESCO and the Equality Act (2010).<sup>25</sup> As such, increasing access to heritage must be taken seriously and be considered as an on-going priority.

As gatekeepers to our sites and stories, it is our duty to make reasonable adjustments and provisions to meet the changing needs of our diverse communities. In terms of dementia-friendly heritage, this means valuing the contribution of people living with dementia and creating multiple levels of support to enable engagement with the collective memory and shared identity.<sup>26</sup>

## 'We want to see these places. They are part of our history. And why shouldn't we go? They are important to us.'

Person living with dementia, member of The Unique's (Service User Review Panel, Gwent)

All heritage sites will be impacted with employees and volunteers who could potentially develop dementia. A dementia diagnosis doesn't necessarily mean a person can no longer do their job. However, dementia is a progressive condition and over time it will increasingly impair a person's ability to work. The Equality Act requires employers to avoid discrimination and make reasonable adjustments to ensure people with dementia are not disadvantaged in the workplace. Dementia is often not considered as a disability, despite the Equality Act specifically mentioning it as one. Employers are obliged to make reasonable adjustments and to consider requests for flexible working from all employees, especially people with dementia under the Flexible Working Regulations (2006). All employees should have a clear pathway of support to ensure they are supported at every stage of their journey. Reasonable adjustments could be switching roles, workarounds, amended duties, memory aids and the use of assistive technology.

In addition to dementia directly affecting employees and volunteers, heritage sites may feel its impact on the workforce as the number of employees with caring responsibilities rises (nearly 1 in 9 employees in the UK have a caring responsibility<sup>27</sup>). Carers are also protected under the Equality Act through 'discrimination by association'. With the stresses and strains that can result from balancing

responsibilities at work and at home, it isn't a surprise that 1 in 6 carers give up work or reduce their hours in order to care for someone.<sup>28</sup> Heritage sites can support working or volunteering carers by creating a carers policy or guideline, encouraging and championing flexible working, allowing time off for caring for dependents or setting up a carers support group.

Despite legal protection, many carers and people with dementia are unaware of their rights. There needs to be a concerted effort to raise awareness of the Equality Act and Flexible Working Regulations within organisations to all employees and volunteers to support them to continue to work for as long as possible. Failing to do so is against the law, as well as being damaging to employers and the wider economy. With an ageing population there is a huge economic case for being dementia-friendly, with benefits including the retention of skilled, experienced staff, reduced recruitment costs, increased employee and volunteer satisfaction, as well as increased productivity and revenue.

#### Key points for 'making the case':

- · Heritage site are immersive environments which help people 'live in the now'
- Heritage sites are seen as safe, familiar spaces, associated with happy times
- Heritage promotes new learning and positive risk-taking29 which supports active ageing30
- Heritage sites offer multiple touch points for social interaction
- Dementia-friendly heritage helps future-proof the visitor offer for existing older audiences
- Dementia-friendly heritage can help generate new visitor audiences
- Dementia-friendly heritage supports income generation, particularly in off-peak seasons
- Dementia-friendly heritage supports compliance with human rights law and the Equality Act (2010) for visitors, staff and volunteers



#### Find out more:

'Dementia Friendly Business Guide': alzheimers.org.uk/download/downloads/ id/3542/dementia-friendly\_business\_guide.pdf

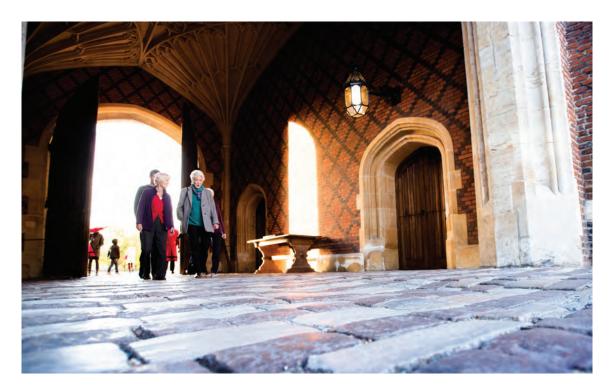
'Creating a dementia-friendly workplace:
A practical guide for employers':
alzheimers.org.uk/download/downloads/id/2619/
creating\_a\_dementia-friendly\_workplace.pdf



### 4. Creating a dementia-friendly visitor experience

People living with dementia and carers want the same things other visitors want: a fun day out that provides opportunities to engage and explore, with minimal stress.<sup>31</sup> Key to creating a dementia-friendly visitor experience is gaining an understanding of the needs people living with dementia may have and integrating this knowledge within the day-to-day practice, staff inductions and refresher training.

This section will share relatively simple steps to help get you started creating a dementia-friendly visitor experience at your site.



#### **Empowering staff and volunteers**

'Although an accessible building is helpful, people with dementia say that it is the people in the building who make all the difference. Friendly, welcoming staff can override the biggest design problems.'32

'The guides are full of enthusiasm, it is brilliant. They explain the information in an interesting way, they are so knowledgeable you can ask any question you like. I like how they are fine to go off on a tangent to follow the group's interests.'

Person with dementia, Chichester Service User Review Panel

Heritage staff and volunteers must feel confident interacting with people living with dementia and carers in order to provide positive customer service and a dementia-friendly visitor experience. This might sound obvious, but misconceptions about dementia can make people feel uncomfortable interacting with people living with dementia.

Across the sector, professionals have cited 'Dementia Friends Information Sessions' as a useful method for increasing awareness and understanding of dementia.<sup>33</sup> Dementia Friends is about learning more about dementia and the small ways you can help. A Dementia Friend learns a little bit more about what it's like to live with dementia and then turns their new understanding into action. This can be very empowering for participants and enables them to think about their interactions with people in general. The sessions also highlight how being 'dementia-friendly' can provide good customer service for everyone, not just people living with dementia.

Staff and volunteers should be encouraged to wear their Dementia Friends badges. With the current figure of two million Dementia Friends<sup>34</sup> across England and Wales, the Dementia Friends forget-me-not symbol is becoming more familiar and recognisable to the general public. If people living with dementia and carers are a bit unsure on arrival, this may help them feel more at ease. It provides an unspoken message that the people surrounding them are aware of their condition and they are welcome.

Fiona Pembroke, Health & Wellbeing Team Leader, Beamish Museum (County Durham), states, 'It can make a big difference if all staff have an awareness of the effect and impact that dementia can have on a person and how to help make their visit as enjoyable and comfortable as possible. Ideally they would all be Dementia Friends and wear their Dementia Friends badges.' Front of house staff wear historic costume at Beamish Museum. The modern Dementia Friends badges would jar with the organisation's living history ethos, so the team came up with a novel approach to displaying their dementia-friendliness. The team crochet forget-me-nots and wear these in place of Dementia Friends badges.

'If someone is wearing a badge or clear uniform, I know I can approach them without a negative reaction. Sometimes it is difficult to tell people as you're worried how they will react. Some people 'physically back off'.' <sup>35</sup>

Person with dementia

Remember to recognise and encourage existing expertise within the team. Front line staff and volunteers build up an amazing social skillset from regular interaction and communication with a diverse range of people. Highlight that



they may already be delivering dementia-friendly experiences and encourage them to take ownership of the positive visitor experience.

The team at Holly Lodge Centre (Richmond, Surrey) deliver regular sensory learning sessions for people living with disabilities and a seasonal programme for older people in their Victorian Pharmacy. Two volunteers researched a sensory soap making workshop after recognising the value of their approach had on participants living with dementia. This has developed into a year-round bookable offer, as well as a desire from the team to offer more dementia-friendly experiences for the local area.

#### **Planning ahead**

Information about onsite facilities is crucial in the decision-making of people with dementia and their carers, as to whether they will visit the heritage site. Gloucestershire VOICE<sup>36</sup>, a group of people living with dementia, mention a 'beautiful setting, nice gardens, historical interest and things to do' as reasons to visit, but highlighted the importance of the practicalities of visiting including:

- getting to the site: public transportation, car and coach parking facilities (cost, distance to entrance, clear signage)
- getting around the site: clear and simple signage and maps (including pictures), walking distances, ramps/lifts, availability of mobility aides and seating, visible trained staff to support
- · availability, location and quality of facilities: catering, retail, accessible toilets
- flexible ticketing or membership options: any available offers that support shorter, more frequent visiting

'I like to be able to talk to a person. When I ring to get information it puts me off if I get given an automated service and not a person to talk to. I like to be able to plan my visit out, prior to going.'

Person living with dementia, member of the Grimsby Service User Review Panel

'Usually one hour (visiting) is enough – I can only take so much information. If more flexible ticket options were available I'd go more.'

Person living with dementia, Chichester Service User Review Panel

Helping people living with dementia and carers plan ahead is essential to getting them onsite. Written information can be particularly helpful as it can be re-read as many times as needed. This can help reduce anxiety and be a memory prompt. It is important to consider the language, style, length and format for written information so that it is easily understood by people living with dementia. When writing for people living with dementia use large fonts, highlight key information (outlined above) and list a phone number that goes to a 'live person' (not an automated system) to encourage people to get in touch to find out more.

#### Avoid written information that is:

- Too long
- Jargon, buzzwords, professional or clinical language
- · Crowded layout or formatting
- · Irrelevant content

Most likely, sites have visitor information available, but it may not be easily accessible to people living with dementia as, often, it is mainly available online (3 out of 5 people aged 75 and above are not online<sup>37</sup>) or at the site itself. Sites may consider putting ads or articles in local newspapers, sending leaflets to doctors surgeries, pharmacies or shops.



#### **Acknowledging challenges**

Heritage sites can be physical challenging. Most sites are probably aware of these access issues which may include cobbles, low light levels, uneven flooring and stairs, limited (or no) lift access. However, there may be added elements like interpretation (for example, soundscapes, projections) and security barriers (such as bag searches, scans) that can cause further anxiety or disorientation for people living with dementia.

The reality is that physical access, interpretation and security barriers may always be issues for heritage sites who do not have the authority, money or influence to change these aspects of the visitor offer. In this case, the best practice is to be honest with visitors about these challenges so they know what to expect and can prepare themselves accordingly. Simple, low cost solutions like printed dementia-friendly signage at key decision or touch points like entrances, exits and toilets can go a long way to reducing stress and confusion. One solution may be creating an access map or repurposing an existing version with additional information that may help people living with dementia and carers negotiate spaces better independently.

'We have a fantastic access guide and map at Hampton Court Palace which focuses on the physical aspects of the building (for example: stairs, handrails, lifts). Our experience delivering Sensory Palaces (learning programme for people living with dementia and carers) has helped us identify additional aspects of the site which people living with dementia find useful to know about beforehand. For example, the Queen's Staircase is dark and heavily shadowed. It is often very busy and loud (voices echo). It can be rather disorientating, but if people know what to expect before entering the space, they can prepare themselves or choose to avoid it. We are planning to work with our Operations team to pull together our expertise to create a dementia-friendly map/trail so people feel more confident exploring the palace independently.'

Kim Klug, Learning Producer, Historic Royal Palaces (London).

Staff and volunteers are the ones who create a warm, welcoming experience, tell stories, create and lead interactive events, guide tours and make time to illustrate how life would have been. Encourage staff and volunteers to recognise when visitors need additional support engaging with the site and to take the time to personalise the visit for them.

'The physical structure of the historic environment may be your restriction but this is when your site staff and volunteers can be your true strength. For every change you cannot make physically, there will be something extra through verbal interaction or additional activities in accessible areas of the sites which will make their visit memorable.'

Emmaline Masterson, Site Manager, Lincoln Medieval Bishops Palace, English Heritage (Lincoln).

Assessing a site's available information and environment can help staff and volunteers improve their understanding of the challenges their heritage site may present to people living with dementia. They can then feel more empowered and proactive to take steps to minimise the impact of these challenges and better support all visitors.

#### Example dementia-friendly site audit:

KEY CONSIDERATION	YES	NO	ACTIONS
Are drop off bays immediately outside the entrance available for anyone who needs easy access?			
Does your car park use gravel or bumpy tarmac that is highly non-stick?			
Is there one clear entrance to the organisation? Do signs from the car park and public transport lead step by step here?			
Is there a map, information point or someone to greet and help outside or immediately inside the entrance?			
Do you have seating areas, especially in areas where people are waiting?			
Do you have somewhere to store wheelchairs or mobility scooters?			
Do you have wheelchairs or walking frames available at the entrance for visitor to use in case they need assistance?			
Are key features like toilets, changing rooms or cafes close to the entrance?			
Are your signs clear, in bold face with good contrast between text and background?			
Are signs at eye level and well- lit? Can they be seen from wheelchair height?			
Are there signs placed at key decision points such as to and from the facilities, the toilets, café or restaurants, outside areas, customer service and payment points clear?			

KEY CONSIDERATION	YES	NO	ACTIONS
Do you have hearing loops? Are they well-advertised or signposted?			
Do you have quiet space for someone who might be feeling anxious or confused, where people can take time out if they need to?			
Is furniture traditional and recognisable in style, rather than having more modern or abstract design features which are not clear of use? Does seating look like seating?			
Are sinks, flushes, taps, and hand dryers traditional and clear of use? Are sensor taps and hand dryers labelled?			
Do you have signs on the inside of the toilet door to direct people back out to help people to easily find their way?			
Are toilet seats of a contrasting colour to the walls and rest of the toilet?			
Do you have handrails to help people get up and off the toilet?			



Find out more:

Dementia Friends:

DementiaFriends.org.uk

'How to help people with dementia:
A guide for customer-facing staff':
www.alzheimers.org.uk/download/downloads/id/2061/
how\_to\_help\_people\_with\_dementia\_a\_guide\_for\_
customer-facing\_staff.pdf



#### Top tips for creating a dementia-friendly visitor experience:

- Attend a Dementia Friends Information Session to increase your awareness and understanding of dementia. You may decide to become a volunteer Dementia Friends Champion which will enable you to deliver the sessions yourself to your teams. Dementia Friends is a great introduction to dementia and can help support individuals creating a warm 'welcome' for people living with dementia and carers.
- Talk to colleagues about dementia to raise awareness through regular briefings, team meetings or awareness weeks. Work together to identify who can champion the 'dementia audience' at your site across teams (Visitor Services, Learning, Curatorial, Collections, Retail, Hospitality, Human Resources). Being dementia-friendly is more of an attitudinal change than anything.
- Invite staff and volunteers to be honest with you about worries they have about visitors affected by dementia. Make time to listen and respond to their concerns. This may help them 'buy-in' to dementia-friendly heritage and improve the visitor experience.
- Be proud of your dementia-friendly efforts! Encourage staff to wear their 'Dementia Friends' badges and promote the work you are doing in printed resources, new stories and your website so that visitors are aware that the site is working towards becoming more dementia-friendly.
- Create easy to read large print information leaflets or accessibility guides to advertise the programming and support available. Advertise these both online and through local services and networks to raise awareness that support is available.
- Conduct an audit of your heritage site with the auditing tool in the Dementia-Friendly Business Guide to understand what barriers and challenges visitors with dementia might have, so you can inform your staff.
- Don't feel defeated if you can't make all the dementia-friendly and access changes quickly or at all. Remember, small changes can make a big difference!

# 5. Partnerships: working together to make dementia-friendly heritage

Whether it is seeking advice, finding an audience or creating a programme, partnerships are essential to implementing dementia-friendly practices.

This section explores how to work with dementia support services, people living with dementia and 'cultural friends' to develop and support initiatives at your site and how they can fit in the wider context of dementia-friendly communities.

#### **Getting support from dementia service providers**

Alzheimer's Society is leading the 'Dementia Friendly Communities' programme which aims to support everyone, from local authorities, healthcare providers, charities and businesses, to 'share part of the responsibility for ensuring that people with dementia feel understood, valued and able to contribute to their community.'38 As such, they are a great starting point for finding out locally what support is available for people living with dementia and how your heritage site could support existing offers.

Dementia service providers can help identify gaps in provision that heritage sites could support. For example, heritage sites across the country, including Compton Verney Art Gallery and Park (Warwickshire) and Soho House Museum (Birmingham Museums Trust), are hosting 'Dementia Cafés' onsite. Dementia Cafés are an increasing popular initiative for both people living with dementia and carers. Whilst these formats may be familiar to the audience, your site may not be. Playing host or offering outreach activities can raise your dementia-friendly profile. HMS Caroline (The National Museum of the Royal Navy, Belfast) supports established Dementia Cafés by bringing object handling and craft activities offsite. This can help get new audiences through the door on a regular basis and build confidence of both visitors and heritage teams.

Maria Flude, Community Participation Officer, Sheffield Industrial Museums Trust, notes the value of hosting a Dementia Café in the Kelham Island Museum which is in one of the city's oldest industrial districts. 'By our very nature we have an empowering subject matter for people with dementia as occupation is a huge part of anyone's identity. We can really indulge that for people who have worked in or known someone who has worked in industry in Sheffield or the region.'

It is important to remember that just as dementia may be new to heritage, the wellbeing benefits of heritage may be new to the health and social care sector. Partnerships may be challenging (our sectors are very different), but working together to meet a shared agenda can help generate an awareness of our work and reinforce the value of heritage in wider society.<sup>39</sup>

One way to keep up with local dementia-friendly developments in your community is by joining your local Dementia Friendly Community. These are often driven by groups called Dementia Action Alliances (DAA). DAA networks vary in size and ambition, but generally they are comprised of a mix of local care providers, businesses and charitable organisations that are committed to supporting people living with



Dementia Café, Kelham Island Museum, Sheffield

dementia. They give heritage sites a platform to share dementia-friendly ambitions and open opportunities for new, and sometimes, surprising partnerships, especially considering a growing number of businesses in the visitor economy now engaging with dementia-friendly approaches.<sup>40</sup>

Beamish Museum, Alzheimer's Society, Go North East (one of the largest bus companies in the region) and British Transport Police partnered to provide assisted travel to Beamish during Dementia Awareness Week 2016, after meeting through the County Durham Dementia Action Alliance. The aim was to help people living with dementia to increase their confidence in traveling on public transportation independently, whilst promoting the dementia-friendly ambitions of Darlington and Durham stations and Go North East.

#### Working with people living with dementia

It's important that people with dementia are supported to influence the development of dementia-friendly heritage initiatives. The value of this process is outlined in the National Dementia Strategy (2009).<sup>41</sup> Whilst the strategy is focussed on health and social care, this practice remains relevant for the heritage sector.

People living with dementia can contribute in a variety of ways: one-off focus groups, on-going advisory panels, pilot project participants and through working with your local Alzheimer's Society. Your local dementia service provider will most likely be able to support you in finding people living with dementia to participate in your planned activities or programme. People living with dementia can be specific about the challenges and help create an action plan for change. This gives you an opportunity to be clear about what may not be possible to change (e.g. installing ramps or lifts, raising light levels). Together, you can develop creative solutions for these challenges.

Everyone with dementia will experience the condition differently, having different challenges and barriers. What might be useful for one person might not for another, and people's needs will change as their dementia progresses. Engaging with a broad user group will ensure programming and places fit for everyone.

Amgueddfa Cymru (National Museum Wales) is actively working with people living with dementia to 'mainstream' dementia inclusion across the museums and historic buildings. The organisation is committed to creating inclusive programming, rather than separate 'special' activities for people living with dementia, and ensuring dementia-friendly adjustments are routinely planned and completed. Amgueddfa Cymru will do this by regularly consulting their newly formed Dementia Engagement Panel, a structured forum of people living with dementia, carers and volunteers who will help shape the work of the museum. Dementia Engagement & Empowerment Project (DEEP) assisted with the development and recruitment of the Dementia Engagement Panel. In the past, Amgueddfa Cymru has worked with their local Alzheimer's Society to ask people living with dementia to carry out dementia-friendly audits of their museum sites.

'By asking us not what you could do for us but how we could work together, you saw that it wasn't about how to solve us – the people with dementia – as a problem, but about you having to change yourselves by engaging with us and giving us a voice, and access to facilities and mechanisms and being recognised, valued and contributing members of society.'

Nigel Hullah, Member of Big Pit's Dementia Engagement Panel



Dementia Engagement Panel, Amgueddfa Cymru

Sharon Ford, Learning, Participation and Interpretation Manager, Amgueddfa Cymru - National Museum Wales, explains how this way of working has impacting the museum, 'Giving people with dementia a voice in the work of the museum has been essential in influencing that work. It has also opened our minds to the potential for employing people with dementia in both voluntary and paid roles.'

#### Partnering with 'cultural friends'

Dementia-friendly programmes are growing in popularity at heritage sites, museums, galleries, theatres and libraries. In addition to looking outside the sector for partnerships, it is worthwhile speaking with local peers about the work they are doing and identify ways of supporting each other.

#### Cultural partners can help by:

- co-ordinating programmes to avoid unnecessary competition of hosting things on the same day/week to ensure variety of activities on different days of the week
- · cross-promoting offers to audiences
- sharing best practice and advice, especially on logistics (e.g. booking participants, risk assessments).

In Edinburgh, Scotland's four national collections (National Galleries of Scotland, National Library of Scotland, National Museums Scotland and Royal Botanic Garden, Edinburgh) came together to develop 'Dementia Socials', a programme of weekly social and cultural engagement provision for people living with dementia and carers. Partners agreed on a schedule: each site would deliver one session per month on a rotation, meaning that for 48 out of 52 weeks of the year there was a 'Dementia Social' available. The partners shared best practice, agreeing to the 'socials' model developed by the National Galleries of Scotland, and tailoring it to fit to their strengths. Partners created a shared leaflet advertising all of the socials across the organisations for six months. This leaflet was available across the four sites and distributed to local dementia support organisations.



Dementia Socials shared advertising leaflet



Dementia Social, Royal Botanic Garden,





Carers at 'House of Memories' training People using 'House of Memories' app

#### Cultural partners can support:

- delivery of time intensive, resource heavy projects which one site would struggle to do alone
- teams emotionally, providing a sounding off board, advice and training for tackling sensitive issues.

The Peer Support Cultural Partnership (Leeds) deliver two 12-14 week projects a year aimed at encouraging people with dementia and their carers to access multiple cultural venues. Partners include Leeds Museums and Galleries, Leeds Libraries, the West Yorkshire Playhouse and Adult Social Care Peer Support Service for People with Dementia. The cultural organisations provide the venues and programmes, Peer Support provide the referrals and on-going support, advice and training for venue staff and volunteers.

Gabrielle Hamilton, Community Team Manager at Leeds Museums and Galleries, notes the value of partnership working: 'The programme is very resource heavy in terms of staffing... which is why it is shared across several venues. [The] support of the Peer Support staff is absolutely crucial.'

Cultural partners may have existing projects that they wish to develop further with using another site's expertise, collections and audiences.

National Museums Liverpool worked in partnership with Hall Place & Gardens (Bexley, Kent) to collaborate on the 'My House of Memories app' and deliver 'House of Memories' training to care professionals and Hall Place & Gardens staff. The partnership utilised National Museums Liverpool's existing 'House of Memories' initiative to enable greater access to the Bexley Museum Collection. Bexley has an extensive collection of social history objects from the local area, but does not have

a large number of items on display. Using the app enables people to actively engage with objects which might otherwise be inaccessible, brought to life through multimedia and memory activities.

The team from National Museums Liverpool delivered 'House of Memories' training at Hall Place & Gardens to local health and social care professionals with the aim of demonstrating how heritage and cultural venues can be accessed to enrich and improve the wellbeing of those living with dementia, their carers and families. Hall Place & Gardens employees also attended the training, giving them a more in-depth understanding of the needs of those living with dementia and their families.

### Top tips for partnership working:

- Use Dementia Connect to find your nearest services for people living with dementia and their carers.
- Join your local 'Dementia Friendly Community' to partner and share best practice with other organisations.
- Create a communication plan to ensure visitors and the wider community are aware of the work you are doing to become dementia-friendly. Think creatively to reach out to isolated groups both in print and online.
- Involve people living with dementia in developing initiatives, but be clear about what is possible within the timescales to avoid disappointment. Word of mouth (positive and negative) travels fast!
- Contact local cultural sites to find out what they are doing for people living with dementia and carers.
- Outline the objectives and responsibilities of each partner organisation in an agreement or memorandum of understanding.
- Communicate and meet frequently to ensure the partnership is meeting the aims/needs of each partner organisation, but allow flexibility and change the agreement if it isn't working.
- Share your dementia-friendly ambition and offers join networks, contact peers, participate in community wellbeing or older people events. Make sure you have leaflets with information and contact details so people know how to find out more.



#### Find out more:

Dementia Connect (finding local dementia services): alzheimers.org.uk/DementiaConnect

Dementia Friendly Communities: alzheimers.org.uk/DementiaFriendlyCommunities

Dementia Action Alliances: dementiaaction.org.uk

Dementia Engagement and Empowerment Project (DEEP): dementiavoices.org.uk/

# 6. Programming for people living with dementia and carers

There is range of programming taking place across the heritage sector that aims to increase engagement with people living with dementia with sites, stories and collections. Offers vary from site to site depending on resource and capacity available.

This section aims to inspire you to take action at your site, by highlighting a range of best practice approaches to dementia-friendly programming.

# **Broadening audiences for existing programmes**

Before starting a new programme specifically aimed at people living with dementia, consider your existing offer. Explore what makes your programmes successful and consider how these existing initiatives could be developed to be more inclusive and supportive for people living with dementia.

Big Pit National Coal Museum is a museum on the site of the former working colliery in Blaenavon, South Wales, part of Amgueddfa Cymru - National Museum Wales. The visit includes a guided trip 90 metres underground with an ex-miner, through various pit roadways and tunnels to visit the coal face. Amgueddfa Cymru's approach to being dementia-friendly is to create more inclusive programming, rather than special events, for people living with dementia.

With this vision in mind, the museum developed dementia-friendly underground tours of the Big Pit mine. The concept of taking people with dementia underground, into places which can be difficult for any visitor, was a challenge from the outset. This was addressed by building a 'welcome' session in at the start of the tour, so that the group has the opportunity to get to know their guide in a comfortable environment, and are able to ask questions to allay any concerns they may have. Following feedback from people living with dementia, the museum team also worked with Google Expeditions to create a virtual underground tour so that participants can see where they will be going before taking the journey underground.

Dementia-friendly underground tours will be a regular feature of the programme at Big Pit, with monitoring and reviews being carried out by the newly formed Dementia Engagement Panel for Amgueddfa Cymru. There has been no dedicated budget to support this work, and thus far, it has been funded from existing site budgets.

The Royal Botanic Gardens, Kew (London) took a similar approach to broadening audiences, noting that that expanding their Health Walks programme to include a dementia-friendly version was an 'obvious option.' The Health Walks, which are popular with local residents, regularly well attended and straightforward to deliver, were easily adapted to increase access. The dementia-



Dementia-friendly underground tours, Big Pit National Coal Museum

friendly version is a slower paced, gentle walk through the grounds and promoted through Alzheimer's Society in Richmond. Otherwise, it has the same framework and logistics as the traditional Health Walk.

# **Creating supportive resources**

Heritage sites may have a variety of collections and expertise available which can be used to create supportive resources for people living with dementia and carers. These can be used to deliver new or existing programmes.

The Scout Association Heritage Service (Gilwell Park, Essex) identified the significant value that the 'plethora of collectables and memorabilia' donated by members and alumni may hold for people living with dementia. They are planning to develop 'Memory Boxes,' as part of a collections rationalisation programme. These can be used to engage people living with dementia onsite and offsite through an outreach programme.

The Museum in the Park (Stroud) delivers fortnightly 'Gentle Park Walks' (developed



From the collection of The Scout Association Heritage Service

#### Rethinking heritage

in partnership with Dementia Adventure and Fairshares, Stroud) which draw on the surrounding environment, a former historic estate. Over the years, participants have influenced some of the planting in the walled garden and inspired staff and volunteers to develop support resources:

- A 'Nature Handbook' was developed by a volunteer to help those who lead walks identify plants and flowers. It is now on sale in the Museum.
- 'Memory Sticks' are literally sticks with elastic bands that are used to fasten leaves, petals and bark collected on the walk. These help participants' record their journey.
- A set of postcards, free to take away, which have an image that might stimulate conversation, for example: a 60s caravan holiday, a steam train, a birthday cake.
   The postcards can be written on and sent home, as a reminder of the day out and a further talking point.
- 'Chance to Chat boxes' are small, sandwich-boxes filled with random items from
  the Museum available for loan free of charge from the Museum and public library.
  These offer a tactile stimulus for conversation at home or when visiting in a care
  setting. This resource has resulted in some people creating their own, personal
  'memory box'.

# **Delivering short-term projects**



Museum in the Park. Stroud



Short-term, targeted projects can be an ideal way to pilot working with new audiences and partners. Heritage staff can build relationships and skills, try out ways for engaging audiences and gain practical experience needed to develop plans for longer-term projects or programmes.



Strawberry Hill House (Twickenham, London) delivered 'Art and Garden Project', a series of creative workshops, to develop and test their approach for engaging people living with dementia. Strawberry Hill House's local Alzheimer's Society (Richmond) identified a gap in local arts provision for people living with early onset dementia. The project included working with two groups (14 people in each group) over four sessions to make individual memory books drawing inspiration from personal memory and the site itself. Activities included: printing and drawing on fabric, telling the story of the house, creating teas, lavender bags and balms with a medical herbalist, exploring the garden and making Christmas wreaths. This experience has inspired the team at Strawberry Hill House to continue working with people living with dementia to explore both the house and gardens. They have recently secured funding for 'Feel Good Garden', a project for two groups of people living with dementia and carers (one group for people with early onset) to explore horticulture and herbal medicine in monthly workshops.

'I have found great pleasure in seeking out things I've never done before – activities like this one are just right for me. It's real food for the soul,'

Person living with dementia and participant in Art and Garden Project



# Outreach: Delivering dementia-friendly heritage experiences offsite

Outreach activities offer opportunities for people living with dementia and carers to access sites and collections in their own environment and help build confidence to visit, if they are able to do so. Working with local care homes, independent living facilities and community groups will bring heritage to isolated individuals who will benefit from the experience.

Chatsworth (Bakewell, Derbyshire) partnered with Nottingham City Council and Nottingham City Arts to deliver 'Armchair Gallery,' a project aimed to make Chatsworth and its wealth of art and treasures accessible to those who may not be physically able to visit, particularly those living with dementia. The team at Chatsworth put together a series of artworks, from a collection chosen by the Duke and Duchess of Devonshire. The artworks were filmed onsite with the main feature being a virtual tour of Chatsworth and the grounds.

These 22 short films were used to deliver eight workshop sessions each at eight different care homes. Each session was facilitated by an artist, following a similar format, incorporating the 'Timeslips' imaginative storytelling framework, a film of one of the artworks, a creative activity (art making, movement or dance) and the opportunity to take a virtual tour of Chatsworth.



Armchair Gallery, Chatsworth

Working in care settings presented challenges like the availability of space, room layout and existing schedules (for example setting up for meals). The team was flexible in their approach, moving sessions as needed, making changes to content (for example, changing background music based on residents' recommendation) and tailoring their approach to fit individuals' needs to ensure that residents receive the maximum benefit from the workshops.

Nottingham City Arts are looking to add more art collections to the Armchair Gallery, develop it into a fully working app and create toolkits and resources to support activity coordinators to deliver in care homes to residents.

"The residents with quite advanced dementia seemed to really gain from... sessions and were able to join in easily – lots of laughter and talking,"

Care home activity coordinator reflecting on 'Armchair Gallery'

The National Museum of the Royal Navy (NMRN) consists of nine sites, both museums and historic ships, which include: National Museum of the Royal Navy, HMS M33, HMS Victory and HMS Warrior (Portsmouth), HMS Caroline (Belfast), HMS Trincomalee (Hartlepool), Royal Navy Submarine Museum and the Explosion Museum of Naval Firepower (Gosport, Hampshire), Fleet Air Arm Museum (Ilchester, Somerset). NMRN is keen for ex-veterans, their families and local communities to think of their sites 'not just places of history but a reminder of comradery, friendship, and national identity which still exists today.'

One way in which they do this is through the delivery of 'Access Days' at HMS Victory and HMS M33. Before Access Days, the Learning & Engagement team visit local care homes and introduce both people living with dementia and carers (family and professional staff) to the sites using object handling, music, movement, drama and storytelling with props. The aim is for people living with dementia and carers to establish connections with the sites, to develop trust between the care homes and NMRN team and to help everyone involved feel confident about visiting ahead of the site visit. Rachel Goodall, Learning & Engagement Officer explains, 'Outreach prior to a visit really helps; it forms a bond, a connection. We can point out relevant information to each individual, making their visit really personal to them.'

# Providing regular dementia-specific programming

Regular programmes that specifically target people living with dementia and carers offer opportunities to change participants' perceptions of the heritage environment and to build new audiences and advocates for your work. These initiatives enable opportunities for measuring the wider outcomes associated with heritage engagement, such as the impact on individuals' sense of wellbeing.

Beamish Museum's Health and Wellbeing Team worked in partnership with Alzheimer's Society to plan, deliver and evaluate 'Let's 'Get Together' at Beamish', a 12-month pilot project (2015/16). The programme offered three-hour sessions every week, in six-week blocks for a consistent group of the 6-8 people living with dementia and their carers. Participants were signposted by Alzheimer's Society,



Lets 'Get Together' at Beamish

who also liaised with the Museum to ensure individuals' needs, requirements and interests were accommodated for ahead of the first session.

Beamish's 'Orchard Cottage', located in the 1940s farm area, served as the meeting place each week, where everyone would have tea, biscuits and toast in front of the fire. Aside from the first session, which was planned by staff at both organisations, activities chosen each week were participant-led; chosen by the group themselves, depending on individuals' interests and abilities. Some activities took place inside the cottage, such as baking, arts and crafts, and reminiscence. Others took place outside and in other parts of the Museum, such as gardening, playing traditional games, walking and exploring the Museum's stored collections.

'Let's 'Get Together' at Beamish' provided participants regular contact with, and support from an Alzheimer's Society's Dementia Support Worker in an informal environment. During some sessions the carers would stay at the cottage with the Dementia Support Worker while the activities were taking place elsewhere which provided an opportunity for carers to share experiences and ask advice. At the end of the six weeks both the Dementia Support Worker and Beamish team were able to signpost people to other groups and services at the Museum and in the local area.

Whilst referrals were slow to start, the increasing number of enquiries and referrals to the service towards the end of the pilot indicated a strong need for this programme within the community. The evaluations were overwhelmingly positive, with the majority of participants feeling that attending the group had made a difference to them personally and also with their relationship with their carer.

The 'Get Together' programme started again in spring 2017 with both Beamish and Alzheimer's Society keen to develop a sustainable service and way to fund staff time and running costs. Beamish will also pilot workshops for carers and relatives that will focus on providing information about dementia and advice on supporting, communicating and participating in meaningful activities with relatives who are living with dementia.

# 'It's reawakened things that have been dormant for a while,'

Person living with dementia and participant in 'Let's 'Get Together' at Beamish', 2016

'Sensory Palaces', a health and wellbeing learning programme at Historic Royal Palaces (London), aims to engage people living with early stage dementia and carers. The two-hour sessions have been running on a regular basis since 2013, with up to three sessions available monthly across Hampton Court and Kew Palaces. During the sessions, participants explore the stories of the palaces in the historic spaces, using their senses. Participatory activities include storytelling, art and music making, dance and performance which encourage new learning, and the sharing of personal stories and knowledge with others.

Historic Royal Palaces (HRP) worked closely with Alzheimer's Society, people living with dementia and carers to develop and evaluate the programme logistics, content and impact. This helped inform the recruitment and booking process, which HRP manages. The experience of running a regular programme for people living with dementia made the team at HRP realise the necessity in creating practical processes for assessing people's level of dementia (individuals can have differing interpretations of 'early stage' dementia), preparing people ahead of the sessions and clear procedures for communicating with participants about appropriate support or services when individuals' dementia progresses.

The 'Sensory Palaces' team book all participants for sessions. This includes speaking directly with anyone new to the programme (usually the carer on behalf of the person living with dementia) to assess the person's level of dementia and any additional needs they may have (for example, physical access). This gives the carer the opportunity to ask questions about the programme and find out if it is right for them (both the person with dementia and carer). The 'Sensory Palaces' team emails participants three information sheets when they book onto a session to prepare them for the day: session outline (timings, short description of activities with photos to illustrate activity), access information (potential physical access or allergy concerns, sensory elements) and arrivals information (directions, maps, meeting point, contact person, suggested attire).

#### Rethinking heritage

Participants' first session is referred to as a 'taster' to try out 'Sensory Palaces'. After attending, they have a short chat with a staff member and discuss their experience. If both the 'Sensory Palaces' team and participants feel positive about the experience, participants are invited to book sessions for the next 12 months. The team manages expectations about continuous participation, informing participants at the start that there may come a time when sessions are no longer suitable to meet their needs due to the progression of dementia. If this occurs, the Sensory Palaces team will speak to couples (people living with dementia and carers) on a one-to-one basis to explore next steps for engagement.

The 'Sensory Palaces' evaluation (2015) indicated that the programme enhanced participants' mood, increased their sense of engagement and gave opportunities to enjoy being with others. The programme is currently collecting data for an academic research project in partnership with the University of Salford. In addition to sessions, the 'Sensory Palaces' programme encompasses a strand for audience advocacy (internally and externally) and sharing best practice. This guide is a result of this work.



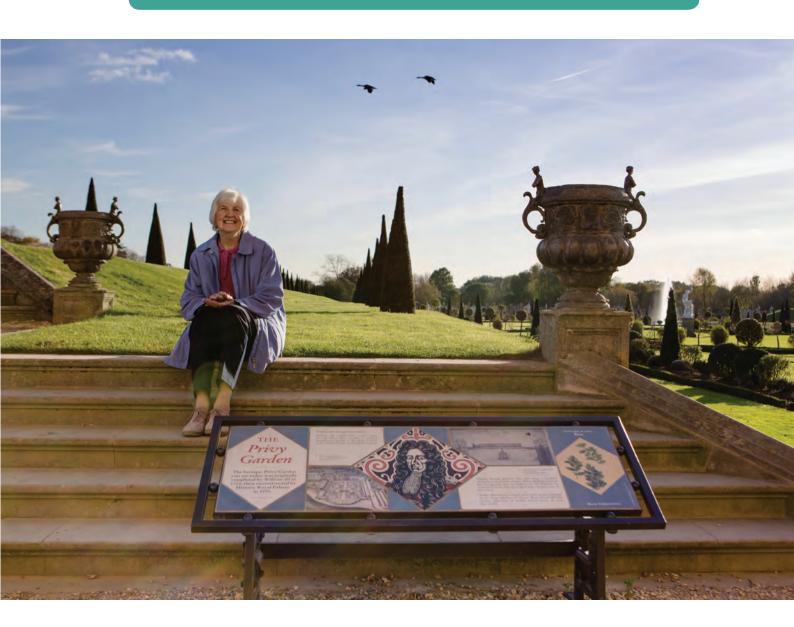
Sensory Palaces, Hampton Court Palace

'It's not just meeting other people, it's increasing our knowledge of history, I think. And then I think the sensory thing is good because it makes an impression on our mind.'

Carer, participant in 'Sensory Palaces' 2015

#### Top tips on programming:

- Look at what you already offer visitors. Consider how you can make existing offers dementia friendly.
- Provide information about the programme in dementia-friendly formats: session outlines with timings and photos, specific access information for each activity, general information (map, suggested attire, contact details).
- Be open in your communications (social media, website) about any limitations of your dementia-friendly heritage offer. If it is only a trial, be clear about timescale and costs. Don't hide information or allow colleagues to hide it because you may initially want to start small.
- Design opportunities for socialising and respite for both people living with dementia and carers.
- Remember to be creative, informal and flexible in your approach to planning and delivering opportunities.



# 7. Overcoming obstacles: common challenges and advice from the heritage sector

Peers in the sector are incredibly generous with sharing their experiences engaging people living with dementia and carers. Thank you to the following organisations for sharing case studies which highlight challenges and offer practical advice for overcoming difficulties:

Amgueddfa Cymru - National Museum Wales, Beamish Museum, Belgrade Theatre, Chatsworth, Compton Verney Art Gallery and Park, Conwy County Borough Council, Eastside Community Heritage, Geffrye Museum, Fitzwilliam Museum, Heritage Lottery Fund, Historic Royal Palaces, Holburne Museum, Holly Lodge Centre, Horniman Museum and Gardens, Leeds Museums and Galleries, Museum in the Park, Museum of Cannock Chase, National Museums Liverpool and Hall Place & Gardens, The National Museum of the Royal Navy, Oxford University Museums Partnership, Royal Botanic Garden, Edinburgh, Royal Botanic Gardens, Kew, The Scout Association Heritage Service, Sheffield Industrial Museum Trust, Soho House Museum, Strawberry Hill House.

CHALLENGE	ADVICE
Getting 'buy- in' from your organisation	Use this resource and the statistics and benefits case in the Dementia Friendly Business Guide to promote your business case for dementia-friendly programming or visitor experiences.
	Outline the long-term ambition and make it relevant for your organisation to gain support. Before presenting your ideas, find what 'speaks' to your senior managers and peers and create a case for dementia-friendly heritage that is supported by facts that they value (for example: social impact, income generation).
Publicising dementia-friendly offers to people living with dementia	Traditional channels, like online marketing can be hit or miss.  Word of mouth and recommendations are often the best way for developing an audience.  Work in partnership with dementia service providers, local media and local networks like Dementia Friendly Communities to promote your offer. If people like it, they will be sure to tell their friends about it.

CHALLENGE	ADVICE	
People living with dementia and or carers worry about traveling to heritage sites	Make all travel options very obvious in your communications (bus route numbers, frequency, taxi numbers, etc.). Signpost people to accessible transport, work with local Community Transport and provide information on booking travel assistance.	
	Be clear about the availability of onsite parking and any costs this might entail.	
People living with dementia	They may wish to speak with someone at your heritage site before attending an event or visiting.	
and/or carer needs additional reassurance	Make sure a contact person and phone number is available on publicity materials.	
before visiting	If it is a general offer, make sure the people answering the phone (for example, reception or contact centre staff) are confident to speak to people living with dementia and carers clearly and sensitively to allay concerns.	
Charging people living with dementia and carers	A lot of dementia-friendly programmes are free, but do not feel this is a requirement. For sites which rely on admission charges, this may not be an option.	
	If charging, be very clear what is charged (for example, 'entry to site costs £x, but activity is free, or carer will pay £x, but refreshments are included').	
	Think about more flexible admission options for example time limited tickets for 1 or 2 hours or year-long valid tickets.	
Staff and volunteers unintentionally upset or confuse people living with dementia and carers	Occasionally, staff have confronted individuals who display unconventional behaviour due to their dementia. This has confused and upset the person, carers or whole groups.	
	Try to frequently repeat the Dementia Friends key messages to staff and volunteers, highlighting that a lack of inhibition may be a symptom of the disease.	
	Suggest staff and volunteers deliver clear, friendly messages to individuals, which is a positive approach to engaging with all visitors, regardless if they have dementia or not.	
	Be supportive of your team, not critical – we don't always get it right all the time!	

CHALLENGE	ADVICE	
Trying to find the best timing and length for activities	Mornings are preferred to afternoons for activities. Make sure to not have activities too early, as people may be slow to get ready for the day. You also don't want to leave it too late, as then the activity will run into lunch time.	
	Most sites tend to run 90 minutes - two hour sessions, starting from 10:30/11:00am. These normally include refreshments and toilet breaks.	
	Decision-making is valued by both people living with dementia and carers, but limit the options or range of activities so people are not overwhelmed by choices.	
Carers creating barriers to engagement for people living with dementia	Carers take an increasingly lead role in making sure the needs of the person living with dementia are met as the condition progresses. In time, it can become natural instinct for carers to speak for the person with dementia or do things for the person without realising they are doing it. Carers may struggle to enjoy the heritage experience for themselves, seeing themselves in support roles only.  Try to converse with and ask questions directly to participants and encourage people to do activities on their own. You might occasionally want to split participants (people living dementia and carers) into groups to do different tasks, but this will depend on the needs of the individuals.	



Auckland Castle

CHALLENGE	ADVICE	
Ensuring the offer matches the needs and expectations of participants (both people living with dementia and carers)	When advertising your dementia-friendly initiative, be clear about who is the target audience: people living with dementia (early, moderate or late stage), carers, or open to public. You want activities to be as inclusive as possible, but it is important to recognise limitations to the support you are able to provide and it was context you are providing this support.	
	Remember that you are not a care professional, heritage sites can be risky or high levels of support may be needed.	
	Invite people to contact you and discuss their needs to see if the offer is right for them.	
	You may wish to work with a dementia care provider to create a system for assessing where individuals' level that isn't too personal and develop robust signposting to other services.	
The dementia friendly project is time limited	Be honest with participants about the terms of the project from the beginning and repeat throughout the length of the project.	
and there are no immediate plans to continue the work	Encourage them to seek out new opportunities and try new things off the back of your project.	
Sharing the value your work with the	Talk to healthcare professionals to understand how they perceive your practice.	
healthcare sector	What language will help them understand the impact and value of this work?	
	What support can you provide their sector (for example, training)?	
	What forum is the best way to present this to them?	
	Being able to articulate the value of your work to another sector may open potential funding streams or partnership opportunities to continue projects.	

CHALLENGE	ADVICE
Evaluating programme impact on participants	Evaluating the impact of activities on people living with dementia can be difficult. Suggested methods:  Ask simple questions before and after activities to gauge participants' level of knowledge or wellbeing: What do you know about (site, topic)? How are you feeling today?  Observe participants in session, note reaction and responses to activities. Write this down directly after session as making notes in the session may make participants uncomfortable. You may consider more structured observation tools, like Dementia Care Mapping.  If working with a care partner, use their established evaluation methods, tailoring them to assess any impact the activities have on participants.  Interview people living with dementia and carers to create participant case studies.



CHALLENGE	ADVICE	
The progressive nature of dementia and how this can impact participants and on-going programmes	Planning ahead is the best way to support the changing needs of people living with dementia and to ensure you meet your programme's objectives.	
	Consider:  Does your organisation have a safeguarding policy for vulnerable adults? Ensure everyone involved with the programme is aware of this policy and their role for upholding it.	
	Expect fluctuating programme attendance. Participants may cancel last minute due to ill health or simply forget to attend. You may wish to plan for this in your project's evaluation.	
	Continually recruit new participants for regular programmes to account for fluctuating participation.	
	Make sure that participants understand from the start that due to the progressive nature of dementia, there may come a time when the programme is no longer appropriate or safe for the person with dementia. Suggest reviewing participation informally (every six to twelve months). Of course, if you have any serious concerns, address these with the carer and/or person with dementia privately. This could be a one-off occurrence, or the incident may signal the programme is no longer appropriate for the individual.	
	Consider 'next steps' for participants. How can they continue to enjoy your site if the programme is no longer suited to their needs? Are there other opportunities you could signpost them to?	
Supporting your team's resilience	It can be incredibility rewarding working closely with people living with dementia and carers, but also emotionally challenging.	
	Make sure to:  Dedicate time to debrief after every session to celebrate what went well and discuss any issues.	
	Talk to trusted managers or peers to discuss any difficulties you may be feeling.	
	Attend peer networks to discuss common concerns and find out new ways of building resilience.	

# 8. Taking action: get started today!

We hope 'Rethinking Heritage' has demonstrated the case for dementia-friendly heritage and inspired you to take action at your site. Now it is over to you to shape what dementia-friendly heritage looks like at your site. Remember, small changes can make a big difference to people living with dementia!

#### Next steps:

# 1. Become a Dementia Friend

Becoming a Dementia Friend will help increase your understanding and awareness of dementia and get you thinking about what dementia-friendly means for your site. You can either attend an Information Session or watch the video online: **DementiaFriends.org.uk** 

## 2. Talk to colleagues about dementia and your site

Get their views on how you can make your site more inclusive and engaging for people living with dementia and carers. This will help you identify internal supporters, as well as those you might need to approach with a stronger business case for dementia-friendly heritage.

## 3. Contact your local dementia support network

- Use Dementia Connect to find dementia services local to you: alzheimers.org.uk/DementiaConnect
- Join your local Dementia Friendly Community to network and share best practice: alzheimers.org.uk/DementiaFriendlyCommunities

# 4. Conduct a dementia-friendly audit of your site

This will help you understand what your site's biggest physical challenges may be for people living with dementia.

- You may wish to invite a group of people living with dementia and carers to your site to explore independently and give you feedback on their experience.
- Use a checklist like Dementia Friendly Business Guide Physical Environment Checklist
  - www.alzheimers.org.uk/info/20079/dementia\_friendly\_communities/361/dementia\_friendly\_businesses or
- Dementia Action Alliance's 'Dementia Friendly Physical Environments Checklist': dementiaaction.org.uk/assets/0000/4336/dementia\_friendly\_environments\_ checklist.pdf

## 5. Audit your existing resources and programmes

This will help inform your dementia-friendly approach.

• Do you already have access maps and information?

- Are there programmes which could easily be adapted to be more inclusive for people living with dementia?
- Check out 'Useful resources' found in the next section.

# 6. Get in touch with heritage peers

This resource is an example of the willingness and generosity of the heritage sector to share best practice. All examples were collected from conversations held in the Dementia Friendly Heritage Group and case studies submitted by peers across the UK.

• Contact us to register your interest in being a part of the Dementia Friendly Heritage Group: Learning.info@hrp.org.uk



# 9. Useful resources and organisations

The following resources and organisations can offer guidance for developing dementia-friendly initiatives. You can also use this list to direct colleagues, staff and volunteers who are affected by dementia and need additional support and advice.

Age UK

www.ageuk.org.uk

Alzheimer Scotland

www.alzscot.org

Alzheimer's Society, Guidance for customer-facing staff 'How to help people with dementia: a guide for customer-facing staff' alzheimers.org.uk/customerfacing

An Alzheimer's Society booklet containing practical advice on communicating with and assisting people with dementia.

Alzheimer's Society training alzheimers.org.uk/training

Alzheimer's Society volunteering opportunities alzheimers.org.uk/volunteer

Alzheimer's Society, Dementia-Friendly Arts Venue Guide 'Becoming a dementia-friendly arts venue: A practical guide' alzheimers.org.uk/arts

An Alzheimer's Society resource providing guidance and best practice examples of the work going on across the country already to support people affected by dementia and using arts venues.

Alzheimer's Society, Dementia-friendly Signage alzheimers.org.uk/downloads/download/2055/dementia\_friendly\_signage This signage can be downloaded and printed to help make your environment dementia friendly.

Alzheimer's Society, Dementia Digital Design Guidelines docs.google.com/spreadsheets/d/1PMlmCkVQvtothQ5JYwP9pJixThJ-nOh7EgiZWer9owM/edit#gid=0

Alzheimer's Society, Guidance for employers 'Creating a dementia-friendly workplace: a practical guide for employers' alzheimers.org.uk/employers

An Alzheimer's Society resource providing guidance on supporting staff members who have dementia or those who are caring for someone with dementia while still in employment.

Alzheimer's Society, Building Dementia-Friendly Communities
'Building dementia-friendly communities: A priority for everyone'
www.alzheimers.org.uk/downloads/download/1236/building\_dementia-friendly\_
communities\_a\_priority\_for\_everyone

Dementia Connect

## alzheimers.org.uk/dementiaconnect

Find local Alzheimer's Society services in your area.

Dementia Engagement and Empowerment Project (DEEP) Guides dementiavoices.org.uk/resources/deep-guides/

DEEP produces a series of guides for organisations and communities who want to work well with people with dementia and support their involvement. These include titles such as Dementia-friendly tips for employers, Choosing a dementia-friendly meeting space and Involving people with dementia at conferences and events.

#### Dementia Friends

#### dementiafriends.org.uk

Alzheimer's Society's Dementia Friends programme is our biggest ever initiative to change people's perceptions of dementia. Become a Dementia Friend by attending an Information Session or watching a short video.

Dementia friendly environments checklist

dementiaaction.org.uk/assets/0000/4334/dementia\_friendly\_environments\_checklist.pdf

Based on work by Innovations in Dementia, this simple checklist looks at physical features such as signage, lighting, and more to assess small changes in your organisation's public spaces which may make a positive difference to your employees or visitors.

Employers for Carers, Toolkit to developing a Carers' Policy employersforcarers.org/resources/toolkits

Gov UK, Dos and don'ts on designing for accessibility accessibility.blog.gov.uk/2016/09/02/dos-and-donts-on-designing-for-accessibility/

Prime Minister's Challenge On Dementia 2020 gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020/ prime-ministers-challenge-on-dementia-2020

SCIE Dementia Gateway Open Dementia eLearning Programme scie.org.uk/publications/elearning/dementia/index.asp

University of Derby, Bridging the dementia divide MOOC derby.ac.uk/online/mooc/bridging-dementia-divide

University of Tasmania Understanding dementia MOOC utas.edu.au/wicking/understanding-dementia

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#### Rethinking heritage

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