Open air museums provide unique opportunities to work with reminiscence for people with dementia. By providing a whole setting of an outdoor area, a house or a flat fully equipped with furniture and objects that can be used, all senses are activated. This book is based on the findings from the EU-funded project Active Ageing and Heritage in Adult Learning where five open air museums and three universities worked together to develop and evaluate reminiscence activities for people with dementia. There are also useful guidelines for other cultural heritage organisations wishing to work with reminiscence activities, as well as suggested course curriculums for providing learning opportunities for relatives or professional carers.
This is a report from the Active Ageing and Heritage in Adult Learning project (2014–2017) funded by Erasmus+.

Editor: Anna Hansen, Jamtli

Authors

Part 1: Anna Hansen, Jamtli

Part 2: Bruce Davenport, Newcastle University; Christen Erlingsson, Linnaeus University; Susanne Bollerup Overgaard, Aarhus University; Areti Galani, Newcastle University, Rhiannon Mason, Newcastle University; Dorthe Berntsen, Aarhus University

Part 3: All project partners


Part 5: Michelle Kindleysides, Tanya Wills, Fiona Pembroke, Beamish and Zsolt Sári, Márta Bokonics-Kramlik, Zsófia Szigethy, Hungarian Open Air Museum.

Part 6: Anna Hansen, Jamtli


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Part 1: Introduction

About the project
The Active Ageing and Heritage in Adult Learning (AHA) project was funded by Erasmus+ and carried out between 2014 and 2017. The aim of the project was to improve the learning offers regarding informal learning, for older adults with deteriorating health and abilities. Five open air museums and three Universities worked together to develop and improve ways of working with reminiscence for people with dementia. The partner museums were Jamtli in Sweden, Maihaugen in Norway, Den Gamle By in Denmark, Hungarian Open Air Museum in Hungary and Beamish in the UK. The participating Universities were Newcastle University in the UK, Linnaeus University in Sweden and Aarhus University in Denmark.

Background: an ageing population
The population in Europe is getting older. An increasing part of the population is over 65, which often means they have left working life. In 2016, 19.2 per cent of the population in EU was 65 or over. This is an increase with 2.4 per cent from 2006. There is also an increasing proportion of people over 80, due to longer life expectancy. In the future this group is believed to increase from 5.4 per cent of the population in 2016 to 12.7 per cent of the population in 2080 (Eurostat 2017A). People live longer and at the same time the age when people choose to have children increases and the number of children born decreases. In 2015, the total fertility rate in the EU was 1.58 live births per woman. The mean age of women at childbirth increased from an average of 29.0 in 2001 to 30.5 years in 2015 (Eurostat 2017B). For the future these statistics mean that fewer people have to care for and support a larger number of people than

1 This part is written by Anna Hansen, Jamtli.
today (old age dependency ratio). This will have financial, social and personal impacts for Europe and its population.

Even though many older adults are active and healthy, there are also people who at some point experience deteriorating health, some of them with some form of dementia. Dementia is a disease in many different forms, but the overall number of people with dementia is increasing. The world Alzheimer report 2015 has found that in 2015 there were over 46 million people living with dementia worldwide. This number is expected to increase to 131.5 million by 2050 (Alzheimer’s Disease International; 2015). There are also many younger people (under 65) who are affected by the disease. It is also a diagnosis which has severe implications for the relatives to the person with dementia. Alzheimer’s association in the US reports that 35 percent of caregivers experience that their health has gotten worse due to care responsibilities, compared to 19 percent of relatives to people without dementia (Alzheimer Association; 2017)

Museums have an important role in society. They aspire to be nice places to visit, a safe public space, a place to learn and active participants in current society. The partner museums in this project were all delivering or planning to develop activities for people with dementia and sometimes also their relatives. They are doing this because they feel social responsibility to act upon and contribute to the two lines of development mentioned above; the ageing population and the increasing number of people with dementia. This has of course both societal and personal impact. If people are given support, stimulation and reason to be active and increase their wellbeing they might also be in less need of care. This will save money for society, and also with an increasing old age dependency ratio, care and attendance might not be possible to the extent needed. Of course the museums do not assume that their intervention will cure the person with dementia or that their activities alone will increase health and wellbeing to such an extent that care can be reduced, but they hope to contribute towards this. However, even more important than the effects for society is the personal perspective. By providing opportunities for people with dementia to have a meaningful activity and an enjoyable time when the focus is not on the disease, the museums hope to increase the feeling of wellbeing and also to inspire some learning.

Project activities

The project comprised three parts. The first one was an evaluation of reminiscence activities at the open air museums. All the participating museums had or were in the process of creating reminiscence activities for people with dementia. All museums had a feeling that it worked well, but in order to increase the quality of their offers more knowledge was needed about the effects of the programmes. An evaluation was carried out which resulted in an evaluation report and guidelines to encourage and help other museums wishing to work with similar activities. These are described in more detail in Part Two and Three of this report.
The second part of the project was a course for professional staff working with people with dementia in care settings. There are some differences between the various countries concerning the medical training, level of knowledge and organisation of the care for people with dementia, which made this group of professional carers quite wide. It was also clear that this is a professional group with little time to set aside for further education and training. The project thus decided to focus on students, training to become nursing staff of some sort, which seemed to be a group more easily reached. The aim was to teach the students how to use cultural heritage with people with dementia in care settings. This is further described in Part Four of this report.

The third part of the project was a course for relatives. The support for relatives varies between different countries, where some countries needed to offer more information about dementia, while other could focus more on use of cultural heritage. The aim was for the relatives to feel confident in using the museums and to create simple things at home for reminiscence. This is described in Part Five of this report.

Learning and reminiscence

The AHA project is about active ageing and learning. Because the group in focus is people with dementia, we had to ask ourselves what we mean by learning in this target group. It is a group that often have memory problems, which make a traditional definition of learning difficult to apply. We have used a broad definition of learning, inspired by Inspiring Learning for All (ILfA), a resource for the cultural sector developed by Arts Council England. They define learning as:

1. a process of active engagement with experience
2. it is what people do when they want to make sense of the world
3. it may involve the development or deepening of skills, knowledge, understanding, values, ideas and feelings
4. effective learning leads to change, development and the desire to learn more

At reminiscence sessions the participants engage with their experience. The sessions are meant to inspire memories and activities by activating all senses, by using a building in the open air museums to provide a whole setting, a house fully equipped with furniture, objects, music, radio, photos, books, smells and anything else. The whole setting also helps people to make sense of various items, since they are put in a context. Making sense of the world thus becomes easier. The ambition is also that the sessions will lead to rediscovery of skills and knowledge, but also development of feelings and understanding. This way the reminiscence sessions touches upon most of the aspects of learning in this definition.

Another inspiration when discussing learning are the Generic Learning Outcomes, also described by ILfA. They identify five different learning outcomes which often occurs in cultural heritage learning. They are knowledge & understanding, skills, attitudes & values, enjoyment, inspiration & creativity and progression & behaviour. In the reminiscence activities the focus is on the enjoyment, inspiration and creativity part, since we aim for the participants to have a good time with us, feeling comfortable and happy. This, we hope, will increase their wellbeing. With a wide definition of learning as a way to bring out memories and to rediscover knowledge and skill you haven’t thought about for a long time, this project focus on wellbeing as an effect of learning.

Naturally, the interpretation of learning and outcomes of learning have to be made in relation to the target group. For this project the primary target group has been people with dementia and the terms wellbeing, active life and learning have to be understood in terms of their lives and capacities. Other target groups have been accompanying carers who comes with the person with dementia to the activities provided by the museums. For the other two other parts of the project, the courses, the target groups are relatives and professional nursing/care staff. For these groups the learning outcomes expected are of course a bit different, but can be seen in the same framework of enjoyment and inspiration, but with a little bit more of the knowledge and skills part.
Reminiscence sessions

The five open air museums which participated in this project all have different conditions. The museums use buildings set in different environments at the open air museums. The buildings represent different times from the 1940s to the 1970s and all objects in the settings can be used. It is possible to make coffee, bake biscuits, make toast on the open fire and many other things. Since it’s a whole environment with sounds, smells, taste and touch involved, it activates many senses and thus inspires reminiscence.

There are of course differences between the museums since they are set in different contexts, socially and culturally. Usually the museums work in similar ways, but with some differences in how they manage the sessions. At Jamtli, for example the same group comes four or five times, leaving time for them to get to know each other and the staff, while in Den Gamle By the participants come from different care homes and do not know each other. In Maihaugen the setting is rural, in a farm, while Den Gamle By has a town apartment. Beamish runs sessions with the assistance of volunteer facilitators and has developed a special group for men, while the Hungarian Open Air Museum is quite new to these activities and is working to find the right form of the sessions to suit them.

For all the museums it is important that everything in the environment is historically correct, so that the sensory impressions work together with the physical settings, and help recreate memories from the chosen period. The museums’ staff are dressed in clothing that is typical of the time period, not always to act a part, even though some museums do that to some extent, but to be a part of the whole historical setting. However, there are some practical needs that have to be taken into consideration. The house, for example, has to be suitable for people with different disabilities, even though it would collide with the historical setting. For instance, access to a toilet and access by wheelchairs is a challenge to fit in and preserving the historical setting at the same time.

All the museums vary the activities to suit the group and to follow the seasons: “Our sessions have seasonal themes. Different props are needed for different seasons of the year. And if we know something about our guest we also try to find props that will be recognizable for the participants.” The museums often engage the participants in craft activities. Often seasonal such as making stockings or decorations at Christmas and decorating eggs at Easter. In Beamish they could also make lavender bags or try some traditional crafts such as knitting or making proggy mats. Depending on the activity they engage in, the participants would often have an item to take home.

During spring and summer, if the weather is nice several of the museums use their gardens. They can sit outside in the garden and water the flowers and plant some things in pots. People can take these away with them or leave them in the garden. Some groups,
who are able, can walk about and look at the ducks, sheep, horses, cows or other animals that are in the museum.

In every session, the museums will plan different tasks the participants can do. They might chop wood, or set the table and prepare the coffee break. Before the session starts, the staff will prepare the house, for example heat up the house, so the temperature is comfortable. In one museum they also produce meatballs on the woodstove, so the house is filled with the smell of food, when the participants arrive. They also bring a house cat and give the cat a dish with milk on the floor. It is also important to find historical chairs for everyone that are comfortable enough to sit on.

How healthy the participants are varies greatly. One museums says: "In a typical session, we don’t set requirements for the level of health in our guests, which means that the degree of dementia in each guest varies widely. We have experienced good responses from guests that were very influenced by their dementia, so it is very important to us, not to let requirements of health be in the way for anyone who could benefit from the experience, even though the guests are of bad health."

Music or singing is an important feature at most museums. It could be playing a piano or organ, singing a song without music or listening to an old gramophone. The museums have different themes for the sessions, often in the form of a suitcase or box with items relating to a specific topic.

In the AHA project all the museums agreed to a common format for a session. The session would follow the same format with greetings, coffee/tea, a tour of the house, and the theme of “a night out/a special day”. Objects, the time period of the setting and what kind of coffee, tea, biscuits or cake to serve varied as well as the objects chosen for the theme. There are cultural and social differences between the countries and locations of the museums, which had to be taken into account.

The session would look something like this:

When participants arrive they are greeted by the museum staff, dressed in period costumes. If the participants do not know each other they are introduced to one another and to the museum staff. They are welcomed and have a look around the building, and
sometimes the garden. This immediately inspires reminiscence, since the smells, objects and the whole environment remind them of various things and they recognize objects, furniture, wallpaper and other things. Coffee or tea will be served and the participants will help grinding coffee beans, laying the table or other things. Conversation will continue during coffee. Objects of the theme are either already placed in the environment or taken out to inspire conversation around that particular theme. This is encouraged by the staff. At some point music or singing will be included, but that will be when it fits into the visit. After approximately 1½ hours it is time for participants to leave. They are given something to take home with them and the staff will say goodbye at the door.

Part 2: Evaluation of reminiscence activities

Reminiscence, wellbeing & open-air museums

Reminiscence is broadly concerned with the evocation of autobiographical memory, and an underlying assumption that this evocation has some therapeutic value for the person doing the remembering. However, the question of whether reminiscence actually has value is contested: What is the impact of reminiscence sessions for wellbeing in persons with dementia (PwD)? Do reminiscence sessions also have an impact on carers? This evaluation looks at the perceived impact in terms of wellbeing and works within practical constraints set by the project and the working practices of the museum partners. The current evaluation focuses primarily on the immediate personal/psychological wellbeing of the participant with dementia as the outcome of interest of the reminiscence sessions and on personal outcomes (including learning) for the accompanying carers. Study design was conceived through a mixed-methods approach.

Summary of contents

The museum partners have different collections and had each developed (or were in the process of developing) their own approaches to working with older adults even before this project began. For this reason, the partners decided to develop a shared reminiscence session which could be carried out, in a culturally appropriate way, in each of the 5 museums. This part therefore starts with a description of the reminiscence sessions which were specifically developed for, and evaluated during, this project.
This is followed by the details of the evaluation methodology and data gathering protocol. The evaluation study design was developed by the University partners in close collaboration with the museum partners. The University partners were responsible for the analysis of the evaluation data. Nonetheless, the evaluation itself had to be implemented by staff at each of the museums and at the same time had to fit within the normal working practices of each museum. Furthermore, the language of evaluation had to work reliably in Danish, English, Hungarian, Norwegian and Swedish. The partners worked closely together to ensure that this took place and the project is, in many ways, an example of a co-produced evaluation. In the end results, recommendations and conclusions are described.

The reminiscence sessions
The goal of the evaluation is to gain insight into the impact of reminiscence sessions in open air museums. Any differences in practice would make it difficult to either compare across venues or aggregate the data into a larger dataset. Therefore, the museum partners developed, with input from the university partners, an outline of a common session. The outline allowed for each venue to work in a culturally appropriate manner and make use of their existing spaces and collections.

Session outline:
• Theme: “Nights out” or “A special day”.
• Duration: approximately 1½–2 hours;
• Focus primarily on objects;
• Welcome/greeting – with national differences;
• Tea/coffee – the participants encouraged to help prepare the food (lay table, grind coffee etc.). Facilitators take care to make sure the participants feel that they contribute;
• During tea/coffee participants are invited into the conversations, which may be about the setting the objects (presented by facilitators that PwD participants can touch and interact with) or the sharing of anecdotes. There may be music and/or singing connected to this;
• Preparation of something for the participants to take home with them (the flowers on the table, left over biscuits, a postcard, Polaroid photos...);
• Facilitators follow participants to the door or gate and bid them farewell.

List of examples of objects that could be used:
• Cinema tickets
• Programs for shows
• Record player + records
• Make up
• Cigarette cases
• Nylon stockings
• Razors
• Handbags
• Hats
• Hair gel
• Dance shoes
• Hip flask
• Perfume/after-shave
• Gloves
• Magazines

The evaluation methodology & data gathering protocol
The evaluation methodology was developed by the university partners, in collaboration with the museum partners. This collaborative approach was essential, especially when considering that the project design meant that the burden of recruiting participants, carrying out the data gathering and translating the data fell onto the museum partners. During the second project meeting, the museum partners were asked to nominate research facilitators, i.e. a lead staff member to work on the evaluation. At the same meeting, the research facilitators were also given a crash course in recruitment and evaluation methodologies, and began to collaborate on the translation of the research documents into their native language.

To facilitate the evaluation process, a data gathering protocol was written by the university partners which guided the research facilitators at each museum through the evaluation process in a step-by-step manner.
All partners agreed that the impact of the sessions would be evaluated in terms of wellbeing outcomes. Various methods for evaluating this are available and many of these involve observational approaches, i.e. watching people for behaviour indicators which correlate with some aspect of wellbeing. However, this requires considerable training time for the evaluators and the current project design did not allow for this. Therefore, a questionnaire based approach was selected.

Furthermore, an ideal approach would be to capture baseline indications of behaviour before participants came to the session. This too was beyond the scope of the project. Partners therefore decided to co-opt the accompanying carers into the process and draw on them as expert witnesses to the behaviour of the participant. This approach is potentially problematic as the carers may well be biased in their observations and in their desire to provide a ‘good’ answer for the evaluation but it considered to be a pragmatic solution given the project constraints.

The evaluation was based on 4 ‘forms’:

- Questionnaire for accompanying carers regarding the PwD participant (Form A);
- Questionnaire for accompanying carers regarding their own experiences (Form B);
- Guide for semi-structured interview with PwD participants (Form C);
- A feedback sheet for session facilitators (Form D).

Forms A and B gather relevant demographic information and a mixture of Likert-scale questions and text boxes for free text responses. The evaluation needed a theoretical framework with which to assess wellbeing outcomes. A published review of observational tools found that the Greater Cincinnati Chapter Well-Being Observation Tool (GCCWOT) was an appropriate measure to evaluate a visual art programme for people with dementia. This evaluation of the AHA project therefore took the domains of wellbeing used in GCCWOT and reconfigured them into a questionnaire format suitable for use in this project.

The domains questionnaire included questions about: interest; sustained attention; positive affect; self-esteem; negative affect; disengagement in the PwD. Each of these
domains was carefully clarified, utilising the behavioural indicators used in the original GCCWOT tool, in order to give the accompanying carers (AC) a good idea as to what we wanted them to assess when looking back on the PwD participants’ experiences during the session. For example, ‘interest’ was clarified as “Verbally or physically indicates interest in others or own work; Engages with others without prompting (e.g. by smiling, making eye contact, chatting, accepting/giving support, etc.)”

This approach was intended to not only provide insight into the ACs’s perception of the impact of the session on the PwD participant they were accompanying but also on how PwDs’ behaviour compared to normal, everyday behaviour.

Form B looked into the caregivers’ own experience of the session, and especially sought information about the ACs’ learning experiences. One question assessed how well the museums prepared the ACs for their role as observers.

Good practice guidelines for evaluation with people with dementia is to include them in the evaluation process and ensure that they are given a voice. This was done via a short semi-structured interview. Form C is the schedule for the interview, which was carried out by the research facilitator either on a one-to-one basis or in a group but with each question being addressed to each participant in turn.

Form D provided the opportunity to for the session facilitators to reflect on their own experience of each session.

When needed, free text responses were translated by museum staff into English. Scans of all documents and translations were uploaded to Filr, a secure file-sharing platform hosted by Newcastle University. Data could then be downloaded by the university partners. Davenport oversaw data management. Bollerup Overgaard led on quantitative analysis. Erlingsson was in charge of qualitative analysis.

Results
The sessions were delivered between September 2015 and October 2016. Across the 5 museums, 129 people with dementia participated in the reminiscence sessions alongside 75 accompanying carers.

Comparing the sessions
It was necessary to assess whether the museum partners had been successful in creating comparable sessions. University partners used interview with facilitators and data from open text responses to assess the similarity of the sessions and concluded that most of the parts in the original outline were found in the structure of the sessions at each museum. Some areas of difference were evident. Without an agreed definition of similarity, it is not possible to decisively prove that the sessions were similar enough to support the decision to aggregate the data. Nonetheless, based on these features, the museums could be said to have succeeded in producing similar yet culturally appropriate sessions.

Demographic findings from quantitative data
The research facilitators at the 5 museums worked through their existing contacts to recruit people into the evaluation study. It is reasonable to assume that the participants with dementia and their accompanying carers are representative of the audiences that the museums normally work with. The quantitative data indicates that the museums have quite different audiences.

<table>
<thead>
<tr>
<th>Museum</th>
<th>Gender</th>
<th>Age</th>
<th>Mean (SD)</th>
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<tbody>
<tr>
<td></td>
<td>Female (%)</td>
<td>Male (%)</td>
<td>61-69 (%)</td>
</tr>
<tr>
<td>Jamtli</td>
<td>50</td>
<td>50</td>
<td>12</td>
</tr>
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<td>Maihaugen</td>
<td>63</td>
<td>37</td>
<td>21</td>
</tr>
<tr>
<td>Beamish</td>
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</tr>
<tr>
<td>Den Gamle By</td>
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<td>15</td>
<td>6</td>
</tr>
<tr>
<td>Hungarian Open Air Museum</td>
<td>94</td>
<td>6</td>
<td>24</td>
</tr>
</tbody>
</table>

Table 1: Demographics of participants with dementia, organised by museum. (Missing percentages accounted for by incomplete responses.) (SD = Standard Deviation)
The participants recruited by Maihaugen were younger than the other museums, the majority of them lived at home, there were more male participants with dementia (unlike the other 4 museums) and they were more often accompanied by relatives. Jamtli, similarly recruited participants who came from home but they were recruited via day-care centres and were accompanied by care staff. Maihaugen and Jamtli stand in contrast to Hungarian Open Air Museum who worked with participants who were all living in care homes and were all accompanied by staff-carers. Beamish and Den Gamle By were most similar – drawing in people from a mixture of settings. With the exception of Maihaugen, the largest age-group at each museum was 80–89. However, Beamish is notable in that none of the participants in the youngest age group and the largest percentage of people in the oldest age group – this is reflected in the higher mean age of participants at Beamish.

Findings from quantitative data regarding outcomes
The evaluation project used questionnaires to ask caregivers, with knowledge of the PwD participant’s normal behaviour, to rate PwD, and their own, experiences. Methodological problems arose concerning the questions on disengagement and negative affect. Consequently, this report does not present any of the data on these domains.
Overall the ratings on the four wellbeing domains (positive affect, interest, sustained attention and self-esteem) were very high after the reminiscence sessions. This applies both to the presence of wellbeing during the session, as well as ratings on how this compared to usual for the PwD. This indicates that the sessions were promoting wellbeing in the moment of the session itself. The data does not provide insight into the long-term effects of the session for the PwD.

The model of wellbeing used in GCCWOT assumes that the different domains of wellbeing are independent of each other. Analysis of the data in this study found very high correlations between the domains. This indicates that ratings on the domains vary together and the domains are related. This suggests that the four domains are overall measuring the same construct – wellbeing – rather than being independent domains.

A few group differences were found:

• Family caregivers were positive, but significantly less positive in their rating than the professional caregivers in all domains.
• Female participants were rated with significantly more positive ratings than males on all domains except attention, where there was no significant gender difference.
• Our findings also suggest significant differences between museums on the ratings of the wellbeing domains (see below).

Across all the sites, the majority of carers found the sessions to be an important learning experience for themselves, although this was not the focused intention of the sessions, and they either agreed or mostly agreed that they had gained new knowledge about how to support wellbeing through reminiscence (see below). Furthermore, almost all the carers either agreed or mostly agreed they had received clear and useful information before coming to the session.

Findings from qualitative data regarding outcomes
The qualitative responses revealed information about the perceived impact of the sessions and provided recommendations for improving the reminiscence sessions. These will be reported separately.

Findings from qualitative data about the impact of the sessions
All three participant groups (PwDs, ACs & facilitators) provided data which confirmed that the intervention elicited reminiscence. For the PwD participants, reminiscing seemed to be an immediate and spontaneous reaction as soon as PwD participants entered the venue.

The preponderance of the ‘further comment’ responses from the ACs were expressions of gratitude, thanking facilitators for a job well done and for successful reminiscence sessions not only for the PwD participants but also for themselves. These confirmed that the ACs perceived the sessions as positive experiences.

AC, facilitators and PwD perceptions were markedly similar about what objects ‘stood out’ at each venue, notably the kitchen and kitchen objects, food and drink, music and song. In general, there was also agreement across all five museum venues but with three notable discrepancies: clothing and photographs were highlighted by ACs but not PwDs; furniture was highlighted by PwDs but not ACs.

Analysis of responses from all three participant groups confirmed that objects stimulated PwD reminding as did the session venue itself.

AC and facilitators’ free text responses support the conclusion that the reminiscence promoted PwD wellbeing during the session. With only two exceptions, PwD participants expressed that remembering past events had been a positive experience. Interviews with PwD contained copious data indicating enhanced wellbeing after having participated in the reminiscence sessions. For example: “And then I think it was nice to see it again and think oh that way, and that has happened and that has happened... and that we then have been able to talk about it and laugh about it.” (PwD, Den Gamle By)

ACs were asked ‘In your opinion, what were the 3 most important things about the reminiscence session for the participant? Please consider what made a difference to them or what stimulated them.’ An appraisal of ‘three things’ responses showed that
comments generally dealt with specific objects, activities, specific venue settings such as the kitchen, conversation and social interaction, and remembering/reminiscence. There were also responses about other aspects of the museum visit, e.g., the journey to the museum, comments about the facilitators etc.

Specific results for free text comments in the form the accompanying carers filled out about their own experience (Form B) were, in general, very positive about the reminiscence intervention. ACs made many positive assertions that they had indeed received information before coming to the session and that they knew what to expect.

ACs were asked whether they found the sessions to be a personally valuable learning experience. Only two (out of 18) responses were actual opinions about this topic, i.e. responses directly related to the statement. These were, “I can always learn something new” (AC, Den Gamle By) and “Learned not just to ask lots of questions about the past” (AC, Beamish).

Seven AC responses to the statement that they had “gained new knowledge today about how I can support wellbeing through reminiscence” indicated that they had gained new knowledge, e.g., “I now know which areas can fuel the conversation in question” (AC, Den Gamle By). In three responses ACs indicated that they saw the session as applying things they already knew.

The ACs were asked to fill in three things that had been most important about the session for them personally. It is interesting to note that AC did not fill in the exact same three things that they had filled in on the form concerning three things most important for PwD’s experiences.

As noted earlier, participation in the reminiscence sessions appeared to enhance the wellbeing of the PwD. In general, PwD described sessions as “cosy” and expressed appreciation for facilitators and their efforts to create a warm and welcoming atmosphere: “It was very cosy... It is very good... So we are feeling well.” (PwD, Den Gamle By). PwDs also described the museum visit as a pleasant outing in itself: “I think it is amazing. Lovely. It has to make you happy, when you see it, it’s fun” (PwD, Maihaugen).

Results strongly suggest point that participating in reminiscence sessions in these museum venues was a holistic experience. When asked to comment on the sessions
the PwD participants often spoke in very positive terms about session events (looking at different rooms in the venue, refreshment time, etc.) that simultaneously involved combinations of several elements: physical action, object handling, sensory experiences (haptic, olfactory, visual, gustatory and auditory) and being/conversing together as a group and reminiscing. Reminiscence sessions in these museum settings were universally described by participants as a very special experience where “All of it fits together” (PwD, Den Gamle By): “Very special. I think this is a really special place. Where else can you go like this? I don't think anywhere is there?” (PwD, Beamish)

Insights into practical issues from the qualitative data
There were 21 responses from PwD and ACs providing specific suggestions for improving sessions. These included:

- more time for each session;
- smaller group size;
- the value of repeat visits;
- the need to take group composition concerning PwD participants into consideration;
- more singing, and talking about early life, and that facilitators should play old records;
- there should be a male facilitator when there are male participants;
- facilitators should listen more closely to the PwD participants and to draw on the information that participants reveal about themselves and use that to inform the content of future, repeat visits;
- concerning the setting venue, suggestions included more seating in the rooms, reducing noise disturbance during session (e.g., due to construction activity at museum), and that (in some sites) the facilities should have better accessibility.

Facilitators were also asked, in Form D, to reflect on each session and this produced several practical reflections and recommendations:

- It can be problematic to maintain conversation and include all the PwD if participating PwD were in different stages of dementia disease;
- Conversation is difficult when many of the participants were hard of hearing and may not have their hearing aids or glasses with them;
- Historic furniture may not be accessible to participants in wheelchairs and dietary constraints may inhibit some participants from fully engaging in the session;
- ACs can hinder a session by arriving late to the venue, being distracted/distracting or noisy.

These issues point to the importance of pre-visit communication between museum staff and carers.

Several issues concerning accessibility at the different museum venues were named that had hindered the sessions, e.g., that the restrooms were too far away from the venue; that the venue was either too cold or too hot for the participants to be comfortable in and stairs to or inside the session setting limited access for some of the PwD. Responses suggested that it was also not easy to get the balance between the available space and the number of participants right.

The session design was also a topic of reflection. It was suggested that session facilitators not sit next to each other. Facilitators commented the time frame for session was often constrained and that, “a little longer session would help.” Many facilitators thought that, “[h]aving the flexibility to have more time” would improve sessions and that, “an extra 15–30 minutes would be good.” Many comments reported that access to more objects would have improved the session but there were also responses that available objects had been enough. Several commented that there hadn’t been enough objects that male participants would find especially interesting.

Others commented on situations where participants had been quiet and not as talkative as expected. Some felt that, “accepting that sometimes things can get a bit quiet” and that, “during these sessions, it is good to have small intervals of silence and just sit and enjoy the moment”. Another facilitator wished, to “… learn something about how I can become
better at communicating with guests, who are very quiet and introverted.” This, along with the earlier comment about dealing with people whose dementias are at different stages perhaps points to the need for additional staff training in some cases.

Other suggestions for improving the sessions included:
• spending some of the session time outdoors,
• “give more freedom to tell their stories even if they don’t match with the planned topic”
• “… put some music/listening to music in the session, … maybe not everyone joins singing gladly without music.”
• “… authentic sound from the radio (mp3)”
• “To have more time with the relatives”
• “Larger pictures in case someone forgets glasses.”

Discussion
The quantitative data indicates that the demographic differences between the participants recruited to the study at each site have an effect on the perceived impact of the sessions. Other studies have shown that the relationship between carers and people with dementia is important for the ways in which the carers assess activities. Care staff may draw on professional knowledge and frameworks to interpret the sessions. Family members who provide care for the person with dementia are known to find caregiving challenging so this may influence the way that they interpret, or make use of, the activities. The differences found in this study are in line with published research and suggest that museums need to recognise these differences in the designs of the sessions that they offer.

The museums all use domestic spaces for their reminiscence sessions. Historically, domestic spaces were strongly gendered. So male participants may not find these spaces and objects as engaging as female participants. This is something that the facilitators noted in their reflections on the sessions.

When these vary with museum, as they do in this study, then it makes the differences between museums difficult to analyse. It is not possible, with the current data, to confidently assert whether the differences between the museums can be attributed purely to differences in the participants or whether they also reflect differences that are intrinsic to the museums. The museums staff should be open to the latter possibility.

The qualitative data provides insight into the factors that PwDs and ACs thought had contributed to the positive outcomes of the sessions. It is important to note that the clarity of responses from the PwDs supports the inclusion of people with dementia in the evaluation process. Furthermore, the differences in ACs’ responses to the 2 ‘three things’ questions indicate that ACs were indeed striving to focus separately on the PwD’s actions and conversation during the session and not simply projecting their own opinions onto the PwD and provides additional confidence in the approach taken in the study.

The responses from participants indicate that they found the sessions to be a rich, holistic experience which extends beyond a conventional object handling + reminiscence session as might be found in a conventional care home setting. They also recognised the special, historical character of the settings. However, the diversity of moments and experiences that PwDs talked about also opens up the possibility that, for the participants, the act of reminiscing may not be of central importance but may be one of several elements, each of which add value to the embodied, social interactions which these sessions foster.

Recommendations for future evaluation projects
The evaluation was co-created through discussion between the museum and university partners. However, it is recommended that, if possible, the evaluation methodologies should be discussed and agreed before the budget is decided upon. In order that the optimal form of evaluation to inform the budgetary decisions rather than the other way around.

Results revealed dissimilar ways of handling the interview situation e.g., interviews conducted with individuals or as a group, number of interviews conducted, and number of facilitators involved in interviewing. It is recommended that more time be given to
Something to eat is an important part of the sessions. Photo: Hungarian Open Air Museum and Maihaugen
training the evaluation facilitators and that project partners to work together to ensure a closer coherence to agreed protocols around interviewing and translating/transcribing qualitative data.

It is recommended that the evaluation projects are used as capacity building opportunities. The projects could be seen as opportunities to train existing staff in evaluation skills as well as training other staff who are interested in working with older adults so that they can back-fill for the staff who have taken on the additional responsibility of overseeing the evaluation process.

The PwDs, ACs and facilitators did not always agree on what objects were important. The data also indicates that the participants are having similar experiences despite the differences between sessions, venues and cultural aspects. It is recommended that future research is needed to explore the reminiscence sessions in a more fine-grained way, to tease out how the different elements of a session support the observed wellbeing outcomes.

Conclusions
This evaluation study was successful in organising five museums in five different countries to deliver broadly comparable reminiscence sessions, notwithstanding cultural differences, which could be compared and generated data which could be aggregated. Furthermore, the study was successful in generating a large enough body of data to allow for meaningful statistical analysis. It is a successful example of a co-created project developed between museum & academic partners across five nations.

The data supports the conclusion that the reminiscence sessions in these open-air museums are perceived by participants with dementia and their accompanying carers as promoting personal wellbeing for the participants during the reminiscence session. Furthermore, the study found that the majority of the carers found the reminiscence sessions to be personally rewarding learning experiences.

The study data therefore provides support for open-air museums to position themselves as partners with care organisations in offering experiences that promote wellbeing.

It also supports the position that open-air museums can play a role in the training and development of care staff.

The focus of the project was on object-stimulated reminiscence but, at the outset of the project, the museum partners asserted that open-air museums offered a ‘special environment’ which was distinct from conventional museums or reminiscence sessions in care homes. The qualitative data supports this assertion. Results provide evidence that the sessions were holistic experiences that depended for their success not just on the objects, but also on the space, the facilitators, and the social & sensory experiences that participants had during the sessions. This suggests that open-air museums could present their work less in terms of object handling + reminiscence and more in terms of a holistic engagement in historic settings.

One of the concerns raised about reminiscence is that it places an obligation upon the PwD to recall information which may cause anxiety. The results from this study suggest that reminiscence was evoked by the setting and the objects without any need for an explicit prompt. Museum facilitators should continue to work through welcoming participants into a social conversation where the setting does the work of evoking memory without making any explicit demands upon participants.

The quantitative data indicates that the perceived impact of the sessions does depend on demographic factors. However, these factors do not account for all the observed group differences in the data. It is suggested that there are differences in the outcomes between the museums which relates, in some way, to the museums themselves. The underlying causes of these differences cannot be discerned from the data. Also, the PwD and ACs do not always agree on what was important about a session. The causes of these similarities and differences could not be explored within the structure of this study and further work is needed, taking a fine-grained approach, to explore how the different elements of a session contribute to the observed outcomes.
Part 3: Guidelines for working with reminiscence in open air museums

For museums and other organisations who wish to put on similar activities we would like to provide some guidelines for how to do this in a good way. Most of the participating museums have long experience in working with reminiscence and this project has contributed to further reflection on how this is done and drawn attention to specific issues which can be improved and how best to work with this.

The Universities’ recommendations
Following the analysis of the evaluation done by the universities the following recommendations are made:

• It is recommended that museums explore the potential for different session content and setting for male and female participants.
• It is recommended that the museums explore the possibility of offering a series of responsive sessions where conversation from one sessions informs the content of future sessions.
• The relationship between the person with dementia and the accompanying carer and (in the case of family caregivers) the burden of care that accompanying carers may be experiencing may be influencing the way that accompanying carers experience and interpret the sessions. It is recommended that museums explore practices which allow for different patterns of engagement (e.g., sessions where the persons with dementia and accompanying carers spend some time on separate activities).
• It is suggested that some session facilitators may need additional support in finding the confidence to accept periods of silence as a positive part of a session and to manage the contributions of persons with dementia whose dementias are at different stages.

The museums’ guidelines

• The whole environment is important. It could be very useful to create “memory boxes” to send out to groups to work with on their own, or to go out to care homes to hold sessions, but what the museum offer is unique since it provides a whole setting which activates all senses and immediately leads to people reminiscing.
• There are socio-economic differences between different countries and even regions, which shape practices more than expected. You can copy the idea, but you have to adapt it to fit your own circumstances and needs.
• It is important to use different techniques in sessions, to have variety and different things that fit different people. Use indoor and outdoor space, physical activities, the use of music and comfort and food are important. The sense of smell is important.
• Reflection and evaluation is important. It doesn’t have to be a large scale evaluation, but all museum staff found it really useful to be “forced” to sit down and reflect on the session afterwards. To formulate what happened and what worked and what needs improving help improve the quality. Important to give priority to this even though staff is always busy and rarely has time for this.
• It is important to think closely about the communication with persons with dementia. You should not ask too many fact oriented questions verbally, but more go for opinions and a non verbal invitation to responses. In that way you will not put them on the spot if they don’t remember or don’t have an answer.
• Spread the knowledge about dementia among all the staff. In some countries there are short training sessions available to make people aware of dementia and how to assist people with dementia. It will be useful if more people than just the members of staff directly involved have some knowledge of dementia if this is a target audience for the museum.
This project increased the respect for the people with dementia. They have a lot of knowledge and sometimes they will end up educating the museum staff about the time period they are discussing. They have a lot of experience and knowledge.

It is important to prepare the accompanying carers before the session. If they know what will happen and what their role in the session is it will run more smoothly. Otherwise you’ll risk they get too engaged and “take over” the session with their own reminiscing.

Part 4: Courses for professional care staff

Many professional staff who have visited the museums with people with dementia find the methods used inspiring. In order for them to be able to work with similar methods on their own a course was created. Another purpose of the course was to enable staff to make use of the museums and other cultural heritage organisations and sites on their own, without a visit facilitated by museum staff. The course is designed for professional care staff and for students in education connected with the subject or with the care staff function. It is a course designed to take place at museums, which have experience with the subject, i.e. museums which already do reminiscence work with people suffering from dementia. However, there is a possibility to give the course at the school if it is impossible for the students to come to the museum, but they will then miss out on the experience of using the museums. The course will differ from museum to museum according to the activities the different museums already use in their reminiscence work. Some museums do activities like cooking or gardening, and others prepare life stories for the participants/guests, some have more than one session per group and so on. These activities determine the course and there is not just one model that covers all museums. The whole idea is that each museum has to make its own program according to their practice. This curriculum will thus describe the outline of a course model that the participating museums found useful. It is a structure with some important elements that can be adapted and changed to suit various museums and other cultural heritage organisations. It is meant as an inspiration for the future planning of courses. First, there is a presentation of the three elements of the course and then, there is an example of a course, including these three elements, put into practice at Den Gamle By. Then follows

6 This part is written by Martin Brandt Djupdræt, Linda Andersen Fog, Lotte Kofod, Henning Lindberg, Tove Engelhardt Mathiassen and Agnete Amlund Rasmussen, Den Gamle By.
a part where our experiences from the evaluation of the pilot courses is summarized.

The duration of the suggested course is three hours. The museum in question decides the time unit for each element and the content, depending on the actual group of staff or students and their background.

Course outline

Element 1: What is dementia?

How to communicate with people suffering from dementia, and how to handle sad memories.

If the participating staff or students are not aware of the definition of the dementia diseases, the course should address this subject.

It is also important to introduce the staff or students to the handling of sad memories, so they know how to react, when sad memories come up. A professional staff person has to be able to deal with tears and sad stories. They have to be able to grasp the situation and the feelings, to appreciate the feelings of the guests, and to be able to respect and talk about the feelings and then comfort the sad person and in the end try to focus on another subject.

Element 2: What is reminiscence?

The way memory works and the theory behind autobiographical memories and reminiscence.

You need to give a definition of reminiscence. A useful definition is:

"Reminiscence is the deliberate use of prompts, for example photographs, smells, music and questioning, to promote the recall of pleasant memories. The focus of reminiscence work is to stimulate the person, provide enjoyment and foster a sense of achievement and self-worth. The anticipated outcomes of reminiscence work are enhancement of the person's quality of life, behavior and mood." 7

An important issue to address is that these prompts evoke the senses; hearing, feeling, smelling, seeing and it is through the senses the memories are awoken.

Then you must address how your museum uses this method. This description can have the following elements:

• Why has the museum chosen to work with Reminiscence methods? Each museum has to explain why and what they do.
• Why is the museum engaged in that kind of work? With whom do you co-operate? (The municipality, a private company, and other museums, the university etc.)
• How the museum got started working with reminiscence sessions
• How the museum finance the sessions. Are the sessions free, or do the visitors have to pay? Can private groups buy a session? Are courses for relatives or volunteers available and so on? It is a good idea to give examples, stories from former visits; it is always nice to hear stories from the real life and not just theories.

If possible, recommend a list of articles, magazines and books or websites, if the care staff or students want more knowledge about the topic. Each museum has to make their own list in each country and language.

An important issue to address concerning the museums’ engagement in reminiscence work is the knowledge of material culture in different time periods. It is this knowledge and the correct historical settings the museum can do through their professionalism which give a depth and a trustworthiness in the settings used in the courses.

**Element 3: How the museum work with reminiscence in practice**

* A guided tour around the museum and a visit to the locations, where you carry out courses for people suffering from dementia.

In element 3, the museum staff shows the museum to the students or care staff in order to inspire and teach them how to use an open-air museum, and other settings and venues when working with reminiscence. Of course the museum staff lets the students or care staff visit the locations for reminiscence work, in order to inspire to reflections on which kind of lives the location depict and what would be specific or general in their or other people's lives of that period. It is important to be able see and reflect on differences.

When the students or staff visit the house, the farm, the flat or whatever place the museum uses, it is important, that they meet a designated and experienced member of the museum staff from the reminiscence group, who will show them how he or she works and will be able to answer questions and share experiences. During the visit the students or staff learn about the historic period depicted in the setting or also learn about the daily life in a flat /house/ farm the group is visiting.

Each museum has to plan their own guided tour around their museum and let the students or staff have a taste of how an ordinary reminiscence session takes place, and hopefully the students will experience the joy of recognition for themselves so they know what the museums are aiming at. As a part of the tour, the museum staff can show the students or care takers other parts of the museum, in order to inspire them to use their own neighborhood, an old shop or a farm, depending on where they live and work. This should be inspirational for reflections about their own methods of reminiscence, when they are not visiting a museum, but having coffee at the home of a person suffering from dementia. A person's home is their own museum filled with possibilities for reminiscence. At the location, where the museum does reminiscence, the students or care takers can touch, try and use everything. Sometimes doing things in practice makes you understand theory much better.

It is very important to mix the theories with examples from the reminiscence sessions, stories from the real life to inspire the care takers or students and make them imagine doing this kind of sessions themselves or make them reflect on situations from their own life.

In this element it’s essential to listen to the staffs’ or students’ stories and include their experience in the session. An example from a session in Den Gamle By was a reflection from a young staff member who saw the toothbrushes hanging on the wall in the kitchen, and understood that this 1950s family used the kitchen as a bathroom. She smiled and said that now it made sense. She was helping an old man living in a modern house with a nice bathroom, and suddenly he had insisted on brushing his teeth in the kitchen instead of using his bathroom, she had been puzzled and did not know what was going on, but now she understood the situation! Making her explain this new knowledge to the group was very useful for them.

The mixture of subjects is up to the museum’s decision depending on the specific museum, the way the museum works and the conditions, educated staff or not, students from a social and healthcare college or an experienced group of staff from a care home or other local conditions, that vary from country to country.

Remember in the end of the course to ask the students or staff to reflect and comment on the course. It can help the participant to reflect and inspire them to share inspirations and ideas how to use this new knowledge in their work. Their comments can also help the museum in improving the course.
An example of a course practiced in Den Gamle By

The following is an example of a course with the described elements practiced at Den Gamle By in Denmark. Most of the groups doing this course are students from the social and healthcare colleges. They have tried to work at care homes for only a short period and have spent most of the time at school.

At Den Gamle By, the museum staff mixes the three elements during the session, which have a total duration of three hours.

Arrival

When a class arrives at the museum, the museum teacher introduces herself and takes them for a walk through the gardens, telling them about the outdoor-reminiscence sessions in the historic gardens.

In this part, we address element 3.

In the classroom

In the classroom, the museum staff introduces the students to the course and the program for the next 3 hours. Then, we sing a classic and well-known Danish song sometimes a children's song or a song about the current seasons, which gives us the opportunity to talk about the importance of music and singing, a way of communication with people suffering from dementia etc.

Then, the museum staff talk about dementia diseases, introduces the definition of “reminiscence”, and explains why Den Gamle By has started this line of work. “We want to be a museum for somebody and not a museum about something”. What we are doing, how human beings remember and how dementia prevents us from getting in contact with memories, who we work together with and so on.

In this part, we address elements 1 and 2.

Visiting the museum and the reminiscence flat

Then, we split up the group and half of the group (12–15 persons) visit an experienced member of the museum staff at our reminiscence flat, where she invites them for coffee and biscuits. The other half has a guided tour around the museum, visiting the interesting spots, houses and venues in order to inspire the students to use other places, and to get to know the museum and maybe find places or interiors, that can trigger their own memory, a flat from 1974, toys or dresses, music or other things.

The group visiting the reminiscence flat is invited for tea and coffee, and the experienced member of the museum staff will show them the flat and tell them how she works with the sessions. She shares her experience with the students, and talks about addressing sad memories. The students can ask all sorts of questions about the flat, the dress she is wearing or the historic period, and how to handle situations. After 30-45 minutes, the two groups switch. At the end of the course, the two groups get together again and are asked to reflect and comment on the course, to make them think about what they have experienced and hopefully learnt, and of course ask questions.

In this part we address elements 1, 2 and 3.

Evaluation

The courses were tried out at all the partner museums during the project and an evaluation was carried out. The evaluation showed that the students and the schools were very pleased with the course, and several schools and museums are now trying to continue the cooperation to make sure this course is included in the students' educational program. In one instance the course was not carried out at the museum, due to long distances and lack of public transport the students couldn't come to the museum. However, this course was also successful, the museum staff bringing objects and photos to show the students how they work, even though they did not get to experience the environment. In conclusion the evaluation showed that the course curriculum described above works very well as a plan for a course, even though adaptions have to be made to suit the individual museum.
The evaluation showed that after the course the participants felt confident to bring people with dementia to visit the museum (92 per cent). This was an important target for the museums, since they want the museums to be accessible for all people, and with the support of the staff it will now be more accessible for people with dementia. After learning more about reminiscence and the museums all participants – 100 per cent – feel confident to bring people with dementia to a reminiscence session at a museum. Experiencing reminiscence on their own was also important, and it was carried out effectively at the museums since 96 per cent of the participants felt they had experienced how cultural heritage reminiscence can bring back personal memories.

Another aspect about being at the museums which is important, in particular for younger people or people who have grown up in other cultures, is basic knowledge about cultural history, history and customs of the past. This is important in order to understand why the person with dementia act in a certain way. The evaluation showed that 74 per cent of the participants feel they have learnt new knowledge about the 20th century, so they can communicate better with people living with dementia. This is also apparent in the comments on what they would like more of in the course, where many of them express that “I lack knowledge on «the old days», songs and carols”.

The courses were successful, since 60 per cent said the course was relevant for their studies and as future carers. 31 per cent said it was partly relevant. One participant says “This course was very useful for me, after this I can better understand the old people and I know now how I can help them in different situations. I have understood the importance of memories too.” With some adjustments and by putting the emphasis on different parts, the curriculum proposed works very well.
Part 5: Courses for relatives

Many family carers or friends of people with dementia find it difficult to find something to do together and difficult to find ways to communicate. Reminiscence and visits to museums could be one activity that could provide a moment of sharing an experience. Museums (and other cultural heritage organisations) could provide the space for these kind of experiences, and how to use it and methods to use can be learnt in a course for relatives.

It would be useful to provide a little bit of information for attendees before they arrive. This could include a little about what the course will cover and directions to the Museum/venue where the course will be held.

Feedback from carers has shown that they are very often the main carer and it would be difficult for them to attend the course unless someone could be with their relative. You could offer to run an activity for participants living with dementia at your Museum while their carers attend the workshop or you could approach carers whose family member attends a regular Day Centre or group and deliver your session at this time.

It may be worth considering running an evening or weekend session if the participants are of working age.

This proposed curriculum provides a structure for a course for relatives, which can be used and adapted by museums who wish to provide such courses. The course outlined take approximately three hours and comprise three modules. The course was tested at the five museums taking part of this project and evaluated. The last part of this chapter concerns the evaluation. The results of the evaluation has been taken into account when creating the curriculum presented here.

Where to look for participants
Initially explore the links that you have made through the sessions that you run. This could include:
• Day Hospitals/Day Units
• National Dementia Organisations/Charities
• Hospices
• Care Homes
• Relatives of participants of any groups that you may facilitate

Also consider members of staff or volunteers in your organisation who have a relative with dementia who would like some more information to help them to support and interact with their relative or friend.

Aims and objectives of the course

Aims
• To give help and advice on improving communication and relationships to families and friends of someone living with dementia.
• To help improve the lives of both the person living with dementia and their carers

Objectives
• To provide information about dementia for families and help improve understanding of certain behaviours
• To give advice on different activities they can carry out with their relative to help improve wellbeing
• To give information which helps encourage social interaction with the person living with dementia

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8 This part was written by Michelle Kindleysides, Tanya Wills and Fiona Pembroke, Beamish.
Structure of the course
The course consists of three modules with module one being optional

Module 1
Information about common types of dementia and their symptoms
This module is optional and does not need to be delivered if your participants already have a good knowledge and understanding of dementia.

Module 2
Reminiscence, Memory and Communication
This module discusses how reminiscence can be a beneficial and enjoyable activity. It also looks at memory and memory loss in dementia and gives tips on communicating well with someone living with dementia.

Module 3
Reminiscence, Communication and Activities both at the Museum and at Home
This module discusses how you can carry out reminiscence and activities at the museum and how you can use the museum with its unique setting and objects to provide activities and reminiscence for people living with dementia.
It also discusses how you can carry out reminiscence and activities at home and gives tips on creating resources to use at home.

The course runs for approximately 3 hours depending on the length of time that you allow for the practical activities.

Introduction
It usually works well to go around the table and introduce yourselves.

Say who you are and mention your experience of working with people living with dementia. Go around the group and ask each person to introduce themselves and if they would like to say who it is that they know who is living with dementia.

It is a good idea to ask them to discuss one activity that they may like to do together.
It is also useful to know whether they live on their own or not.

Explain that we are not trained dementia experts but have experience of working with people working with dementia.

Also mention that dementia can be an emotive subject and if anyone feels that it becomes too much they are welcome to leave the room should they feel the need.

Module 1: What is Dementia?
Explain that dementia describes a set of symptoms which can include memory loss, difficulties in thinking and planning and difficulties with problem solving or language.
Dementia is caused by diseases within the brain.
It can be helpful to give a brief overview of the most common types of dementia and their symptoms.

Alzheimer’s disease
• Caused by build-up of proteins in the brain interrupting the connections
• Most common type
• Main symptom memory loss
Other symptoms may include difficulty in finding the right word, solving problems and making decisions

Vascular Dementia
• Caused by reduced or blocked Oxygen supply to the brain, often following a stroke or series of mini strokes
• Symptoms will vary depending on which part of the brain is affected but can include problem solving and planning, concentrating, and thinking quickly
• Can have times when they are very confused
Mixed Dementia
• This is when someone has more than one type of dementia and therefore has a mixture of symptoms. e.g. You can have Alzheimer’s disease and Vascular Dementia together.

Dementia with Lewy Bodies
• Abnormal structures develop within the brain cells and eventually cause the cell to die leading to dementia.
Common symptoms include:
• Difficulty with perception
• Fluctuating alertness
• Hallucinations
• Difficulty with movement

Frontal Temporal dementia
• Caused by abnormal clumps of protein forming within the brain cells and causing them to die in the front and side parts of the brain.
Common symptoms include
• Difficulty with language
• Personality changes
• Changes in behaviour

There are many recognised organisations that have very clear explanations of the symptoms and resulting behaviours of dementia that can be accessed to expand this information.

It is also important to include some information about organisations that can support people living with dementia and their carers.

Module 2: Reminiscence, Memory and Communication
Reminiscence
Before discussing reminiscence it can work well to allow the participants to experience reminiscence without realising that they are doing it.

A reminiscence box with objects and artefacts form more recent eras such as the 1950’s, 1960’s, 1970’s, 1980’s and even 1990’s can be used for this. The age of the objects will depend on the ages of the participants but a mix of several eras is usually successful. The objects can be put on the table with the simple instruction to have a look at anything if they would like to. This usually produces spontaneous reminiscence, stories and conversation within the group as well as laughter. This activity can allow the group to feel the enjoyment that reminiscence and social inclusion can bring.

Memory boxes can have many different themes. Photo: Jamtli.
Following this activity the group can be made aware that they have just spent time reminiscing and the definition of reminiscence can be discussed.

“The act of remembering events and experiences from the past”

You can then go on to discuss the value of reminiscence for people living with dementia.

**Why reminiscence can be valuable for people living with dementia**

Key points to include:

- The world can be a very confusing and distressing place for someone affected by dementia. They may be seeing and doing things everyday but they don't always make sense because of the damage to their short term memory. They may not recognise familiar people, places or surroundings.

- Trying to focus communication that allows people to use their longer term memories, the memories that they are confident in using and more able to retrieve, can help people to reconnect with their sense of self, to help improve their self-confidence and help them to engage and communicate with others.

- If we are constantly asking people questions and talking to them about very recent things, the things that they struggle to remember and recall, then very quickly people will lose the self-confidence to communicate with others and could become very socially isolated, frightened and depressed.

**Tips for using reminiscence**

- It is important to try not to just ask lots of questions to people about their past, such as “Do you remember this? “Can you remember where you went to school? What was your teacher’s name? Who were your friends?” Every time you put someone ‘on the spot’ like this their brain has to work very hard to go through all those drawers/bookshelves to retrieve the information. As we get older we will have even more drawers/shelves to look through so it will take us even longer. Asking lots of questions may also make people feel like they are being tested and failing at the test if they can’t remember the answers.

- Instead, try to initiate conversations and allow people to access their memories in their own time, more naturally. Very often, if we start a conversation about some thing, such as going to the cinema, then people will join in if they feel comfortable and able to.

- Try to use a variety of senses to help people to engage and retrieve information. For example when we ran the sessions about ‘Nights Out’ we had photographs (vision), objects (vision and touch, smell), music (sound).

- Recognising is easier for people than recalling. Simply asking someone in an empty room about where they went on nights out would be very difficult compared to the way we do it in our sessions, where we have lots of recognisable, sensory things.

- People might tell you the same things over and over again. Be patient and don’t tell them they’re repeating themselves. It’s great that they want to talk and it’s obviously something really important to them that they want to share.

- Even if people can’t remember facts or remember details of what they’ve been doing, the emotions connected to these things will be remembered much longer. For example if someone has had a lovely experience on a day out and they have enjoyed themselves, this sense of happiness will stay with them for much longer. This also means that if someone has had a negative experience then the emotions attached to this will stay longer too, such as fear, upset, anxiety, anger.

**Memory**

Often relatives who are caring for someone living with dementia find it difficult to understand why the person can remember some things very well but cannot remember what they had for breakfast. Explaining memory and memory loss can help relatives and carers to understand why a person living with dementia may remember some things and not others.
How memory works and why it is important

Key points to include:

• That we all store memories in our brain from the moment we are born
• Our memory store is like filing cabinet or bookshelf. We store more and more as we get older, with newer memories in the top drawers/shelves
• Our memory helps us to do everything, eg who we are, where we live, who are these people in our lives, how to get dressed, how to get to work etc
• We have shared memories with others in our lives, especially shared family memories, eg weddings, birthdays, holidays
• Memory doesn't just involve one sense, it involves our brains storing lots of information about what we see, hear, touch, smell and taste. An example might be a birthday party. We remember a birthday party we might remember what the room looked like, who was there, what food we ate, the music we heard and danced to, the smell of someone's perfume or the smell of the village hall etc. Just engaging with one of these sense, eg the sound of the music, can then trigger our brains to retrieve all the other bits of stored information to produce a larger, richer memory of the whole birthday party.

The impact that dementia can have on our memory

A really useful website is provided by Alzheimer's Society (UK). This website also has lots of YouTube clips that explain about dementia in a really clear and concise way

Key points to include:

• Dementia can affect any part of the brain. Not all forms of dementia affect our memory but types such as Alzheimer's Disease (which is the most common) will affect memory
• Short term memory is affected first
• Use the idea of the filing cabinet or bookshelf to help explain. Information that we have stored most recently, ie that day, week or month, will be in the top few drawers.
The impact of dementia will mean that some of the information in those top drawers will become lost or ‘stuck together so that you can’t read them’. If you’re using the bookshelf idea then the books of the top shelf are your most recent memories and some of them will start to fall off.

- Not all the information vanishes straight away. It is often a gradual process and memories aren’t lost ‘in order’. For example, someone might not be able to remember what they had for breakfast but they will remember that they have a doctor’s appointment that afternoon.
- As dementia progresses more and more of the drawers/shelves will be affected. This is because more and more brain cells are being damaged.
- Long term memories, e.g. childhood, early adult life, will stay intact much longer.
- Some people will experience a rapid decline in their abilities, for others the decline will be a much more gradual process, over several years.
- Dementia doesn’t just affect older people. Not all old people will develop dementia, although the chances of developing it do increase as we get older. People as young as 30s/40s can develop forms of dementia too.
- Dementia doesn’t just affect the part of the brain that controls our memory. It can also impact on the ability to speak, to listen and process information, to move, to see etc.
- So even if people aren’t speaking to you they may still be thinking about what they would like to say or do, so we need to support them to communicate in different ways.

Communication

Often people find it difficult to communicate well with someone living with dementia. A few simple tips on helping to improve your communication can make a difference to your relationship with that person and to the quality of that relationship.

Tips for communication

Key points to include:

- Try not to ask lots of questions, instead try to initiate conversations and encourage people to join in.
- Think about the space you are in – are there lots of distractions? Is it quiet? Is it comfortable? Are there memory prompts around?
- Language can be a challenge for people so try to involve a variety of senses and don’t just rely on speaking. Can people point, nod/shake head at things? Can they demonstrate/do things rather than just talk about them?
- Try to do things with people or help them to do things independently, not for them.
- Give people time to answer. Just because they’re not saying/doing anything straight away, doesn’t mean their brain isn’t working.
- It’s tempting to jump in and talk for them, but listening is very important. If you think people are struggling to communicate then you could try offering prompts, but try not to talk for them or over them.
- Try to use simpler language and short sentences, but without sounding patronising.
- Our eye contact and body language is important. Show people that you are interested in them. The ability to read non-verbal communication stays intact much longer.
- Sit close to each other, don’t try and have a conversation with someone on the other side of the room.

Module 3: Reminiscence and Activities at the Museum

This section of the course gives information on how using the museum can be a helpful and enjoyable activity. It also gives tips on planning visit to the museum.

Talk about the activities that you might use in a session at your museum. It can be very successful in getting the feeling of engagement across if you actually carry out a few of the activities with the participants.

The welcome with Tea and Toast or Coffee and Cake can demonstrate the feeling of welcome and inclusion that we aim to provide during our sessions.

Using music and singing can also demonstrate the enjoyment that this can bring.
Key points to include:
• Talk about the sessions that you provide at your Museum. You might want to show pictures, read quotes. You might want to talk about a particular session/group you work with and give examples.
• Talk about why you do what you do. For example, why it’s important for everyone to sit around the table together, why it’s small groups, why you have certain things in the room. What can people do in the sessions? Try to relate this to the things discussed earlier in the module
• What works well and why?
• What makes sessions at the Museum so unique and special? Can you give examples of participants who have noticeably changed in behaviour or spoken for the first time etc?
• Talk about things to look out for as you walk around the site
• Discuss ways to start conversations without lots of questions. This can work in one of the sessions or if they visit the whole museum site as a group. For example if you keep saying ‘do you remember this?’ it could start feeling like a test and the person living with dementia could feel like they are failing. It is much better to say ‘that is an interesting object’/’I wonder what it could be....’ etc, that way you leave it open for the person to talk about it if they know what it is or pass over it if they don’t.

Planning a visit
Aim to explore ways that a visit can be valuable and enjoyable. Help carers to identify and overcome any potential challenges to visiting the museum.

Go over what might worry the family carers about visiting the museum. Try to alleviate those fears by offering suggestions as to how they may overcome to problem. It can work well to take ideas and suggestions from the group as well.

Also discuss a visit that isn’t going well. It may be best to go home and try another day. What if the memories are upsetting? Tears are ok when we remember people we love that have died. If someone is getting distressed it may be best to move on from that area or to try and use some kind of distraction.

Discuss tips for planning a visit such as:
• Visit a small area rather than trying to get around the whole museum in a day. This could be tiring for the person living with dementia and also the carers. It could also be too much stimulation for the person living with dementia and could become overwhelming.
• Plan where you can have a drink, snack or lunch to avoid the stress of having to look for somewhere last minute. You could bring a packed lunch if you would like to avoid queues and crowds in the cafes and restaurants.
• Plan in time to rest during your visit, finding a quiet area to sit. Also discuss different ways in which the museum could be used to provide an enjoyable day out.

Key points to include:
• Just going for a walk around the ground is a nice day out and can be used as a safe place to go for a bit of exercise and fresh air.
• Choose one building to go into and try and guess who lives there. Use the objects to guess if it is a family/young or old people/what do you think they work/what could their names be etc. Using imagination is fun and it is helpful for the person living with dementia as they often feel they don’t know the answers to questions in life. With this game all answers are right and make up part of an interesting story (Beamish Museum can give you more details about how to do this)
• Take photographs around the site. It is a fun hobby and gives you something to look
at later. This can lead on to other activities to do at home such as making an album or scrap book.

• If the person living with dementia can paint or draw the museum is a nice safe place to do this outdoors with a lot of interesting areas to use in the drawing.

• Visiting the animals (if the museum has any). Animals are very therapeutic and are known to have a calming influence. Can also be useful for reminiscence if the person used to look after pigs or horses etc.

• What ideas can other people in the group come up with?

Reminiscence and Activities at Home

This section of the course discusses how to use reminiscence at home and suggests some enjoyable activities you could do together

Key points to include:

• Reminiscence doesn’t have to be at a Museum

• As a relative you know the person living with dementia extremely well

• You will probably have access to old family photographs, items from their earlier life

• All of these can be used as the starting points for conversations and activities with your family member

• It doesn’t have to just rely on speaking and seeing. Are there activities they used to enjoy doing, can they still do them with a bit of extra support? For example baking, helping in the garden. Through doing these activities people are still using their memories and engaging different senses. You could then perhaps initiate a conversation while doing the activity. For example if baking you could start by saying “You always used to make beautiful birthday cakes, my favourite was the Fairy Castle…” If the person remembers this then they will join in, if not then maybe wait a while and start another conversation. The conversation doesn’t always have to be about the past. Simply encouraging people to interact with others and things around them is important. If you don’t use these skills then you will eventually lose them.

Creating reminiscence boxes at home

Key points to include:

• You could create your own reminiscence box to use with your relative. Anything relating to their earlier life, family and work will be great. It doesn’t have to be just photographs, are there newspaper articles, magazines, objects

• You know your relative better than we do so these boxes can be really personal and unique to your family. It could be a family activity to put them together.

• If you are using photographs & objects it might be easier to limit these to a few at a time as it might be overwhelming to just go through a big box of photographs spanning over 50 years. Perhaps focus on one theme? But everyone is individual, so you might have to try a few things and see what works best for your relative

• Have the box somewhere easy to get to so that you can use it whenever you think would be good. Perhaps your relative might want to also look through it on their own or with other people.

• Encourage younger children to get involved. Allow older people to feel valuable by passing information and family stories onto younger generations.

• It might be nice to involve a few other family members, as people often remember different things about a shared memory, and this helps to jog each other’s memories and build up a really rich memory of something together, eg a family holiday.

• If you are involving others make sure that the person with dementia doesn’t get left out and they are given plenty of time and opportunities to speak.

• You can add to your reminiscence box all the time. Perhaps you went to the beach recently. This doesn’t mean that the person with dementia will instantly forget all about this when they get home. Perhaps keeping some shells and photographs of you all on the beach might help them to remember bits of this or at least look at the photograph and recall a sense of happiness, love and security.

You may want to summarise the most important points at the end of the workshop and also ask if anyone has any questions
Resources
You may also want to provide written information for participants before or after the workshop to sum up what you’ve talked about, or ask people to make notes if they like. You could let them know of other organisations and websites where they can get more information.

Evaluations of workshops for relatives
An evaluation was made of the pilot courses which took place in the five partner museums participating in the project. This was made in order to make sure the curriculum and future courses are of high quality and meet the needs of the target group.

Gender
Most of the relatives who participated in the workshops were female. Statistics proved, that females tend to live longer, therefore they can look after for someone longer.

However, in most of the museums there were more people with dementia who were female than males. This also can be explained with ageing; women are more likely to reach a higher age and because they live longer, they have more time for dementia to emerge. Thus, it is important to make sure, when planning your session, to use objects that can be related both to men and women during reminiscence.

Age
Concerning age, most of those who attended the workshop were in their ’70s or late ’60s.

It is useful if you can be informed before the sessions about the age of the relatives, so you can prepare objects, food and music etc. that was common in the era when the participants were young. This way participants can experience reminiscence as well, even without realising that they are doing it.

Relatives
While many people are looked after by their wife or husband, there is a big variety in how the person with dementia and their carer are related. All in all we can say, that usually family members take care of people living with dementia, not friends or neighbours.

In those countries where people living with dementia can manage to live in their own homes they most likely live with and are looked after by their spouses.

It’s really important to draw more attention to dementia concerning those who don’t have a relative living with this condition. The whole society is influenced by the causes of dementia on different levels. There is a chance for everyone to meet a person living with dementia in a store or on the streets, so it’s important to know how to handle the situation, even if you are not closely related to that person. So those who don’t have direct relationship with people living with dementia should also be allowed and encouraged to take part in these types of courses.

This part is written by Márta Bokonics-Kramlik, Zsolt Sári, Zsófia Szigethy, Hungarian Open Air Museum.
Living at home or in care facilities

While in Sweden and Norway most of the people who live with dementia live in their own homes, in the UK it’s almost half and half, meanwhile in Hungary all the people are in care-homes. In Hungary by the time people get diagnosed with dementia they most often have (severe) other problems, so it’s common that their relatives decide to take them to a care-home, because they can’t manage to look after them.

Communication

From previous experience the museums felt that communication between the person with dementia and the relative is sometimes difficult. We asked the question: “Did you learn anything during the workshop that will help you in communicating better with your relative?” The answers to this particular question are very important, because this is one of the things where we can give some extra support to the relatives. They can read and do some research about dementia (the illness itself) on their own, but it’s our role to give them tips on how to communicate better with people living with dementia. It’s really important, because with proper communication they can make their own life happier, calmer and less frustrated. So it’s for their own good too. Through the communicational methods we are able to give them tips about how to be more patient and how to enjoy spending time together with their relatives. It’s an important aspect to know, how much time they spend together, so we can give different advice to those who live together and spend a lot of time together and to those who only visit their relative in a care-home once in a while.

Useful learning

If we look at the free text answers that were given to the question “What were the three most useful things in this workshop?” they are mostly referring to the new methods they learned about communication and reminiscence. It worked very well, when the carers themselves were able to experience how objects and music can trigger memory and how reminiscence works. Through experiencing, having the ‘aha effect’, they were able to understand more how it functions with their relatives dealing with problems caused by dementia.

Here are some examples from the given answers:

• Preparing a memory box.
• Using photographs and objects.
• Involving others (family and friends), allowing and encouraging the person to do things for themselves.
• To have more understanding and patience.
• Talk to others who are in the same situation, share experiences.
• Tips on how to communicate better.
• How to use all the senses to trigger memory.
• Realising how to be more helpful.

These comments also reflect that the participants felt the course was useful to them. As we can see there are definitely positive answers to the question “Will you make use of the knowledge you learned today?”

It can be very useful if you talk about and give advices how to handle different situations, how to treat your relative living with dementia in specific situations.

Cultural heritage
Since the museums believe that cultural heritage and the environment they provide is beneficial to the participants we asked “Do you agree: museums/cultural heritage can help to improve the wellbeing of people living with dementia?” This was once again a very important question. The answers prove that people agree and see how cultural heritage and museums can take part in social responsibility and help to improve the wellbeing of people living with dementia.

Conclusions
The evaluation showed that the relatives to people with dementia find it useful to meet other relatives and discuss their situation. They also much appreciate the use of cultural heritage and experiencing reminiscence on their own. The course curriculum includes several of the points brought up in the evaluation.
from some more training in handling their stories and also how to cope with regular participants with dementia having deteriorating health or even dying.

An area which would be interesting to develop further is sessions for couples. Developing methods which more actively puts focus on the couple, and not only the person with dementia and the relative as an accompanying carer, could be beneficial for their relationship and the learning for the person without dementia, since we have seen many positive effects on them too. This could also be extended to programmes for whole families, giving the whole family a better understanding of the person with dementia and giving them a meaningful activity to do together, which is hard to find. In many families children and grandchildren are also effected by the illness and it might be useful to focus on their understanding of the illness. It’s also important to see the person with the illness as a person, which the reminiscence activities brings out.

References


Alzheimer’s Society (UK) www.alzheimers.org.uk


Appendix 1: Quantitative data

Quantitative data about the persons with dementia’s four wellbeing domains (interest, positive affect, sustained attention and self-esteem).

Total number of participants: 118. For respective museum the number of participants were: Beamish: 32, Den Gamle By: 32, Jamtli: 18, Maihaugen: 19, Hungarian Open Air Museum: 17. The number in tables are shown for each museum and then in total and in percent of the total number.

Interest
Verbally or physically indicates interest in others or own work; Engages with others without prompting (e.g. by smiling, making eye contact, chatting, accepting/giving support, etc.)

Question to the accompanying carer: Participant showed interest through engagement with others (smiled, made eye contact, chatted, accepted/gave support, etc. . . . )

<table>
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<th>Beamish</th>
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<th>Jamtli</th>
<th>Maihaugen</th>
<th>Hungarian Open Air Museum</th>
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Question to the accompanying carer: Based on your personal knowledge of the older person in everyday life, do you consider that the participant showed “interest” during the reminiscence session as:

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**Sustained attention**

Sustains attention to task or activity; Returns to task/activity after verbal prompt (if distracted)

Question to the accompanying carer: Participant maintained sustained attention.

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**Positive affect**

Relaxed body language, smiles and laughs; Verbalizes sense of pleasure, enjoyment, being happy (e.g. by smiling, laughing, being relaxed, etc...)

Question to the accompanying carer: Participant expressed/displayed positive affect.

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<th>Jamtli</th>
<th>Maihaugen</th>
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</table>

**Self-Esteem**

Non-verbal expression of pride; Verbal expression of satisfaction; Positive reminiscence about self; (e.g. by clapping, smiling, nodding, etc.)

Question to the accompanying carer: Participant expressed self-esteem verbally or with body language

<table>
<thead>
<tr>
<th></th>
<th>Beamish</th>
<th>Den Gamle By</th>
<th>Jamtli</th>
<th>Maihaugen</th>
<th>Hungarian Open Air Museum</th>
<th>In total</th>
<th>In %</th>
</tr>
</thead>
<tbody>
<tr>
<td>All the time</td>
<td>13</td>
<td>6</td>
<td>10</td>
<td>1</td>
<td>12</td>
<td>42</td>
<td>35,9</td>
</tr>
<tr>
<td>Most of the time</td>
<td>16</td>
<td>16</td>
<td>10</td>
<td>8</td>
<td>10</td>
<td>55</td>
<td>47,0</td>
</tr>
<tr>
<td>Some of the time</td>
<td>3</td>
<td>8</td>
<td>6</td>
<td>10</td>
<td>5</td>
<td>55</td>
<td>47,0</td>
</tr>
<tr>
<td>Not at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>17</td>
<td>14,5</td>
</tr>
<tr>
<td>Don’t know/not sure</td>
<td>2</td>
<td></td>
<td>1</td>
<td></td>
<td></td>
<td>3</td>
<td>2,6</td>
</tr>
</tbody>
</table>

The methodology & data gathering protocol is described in [Part 2: Evaluation of reminiscence activities](#).

Question to the accompanying carer: Based on your personal knowledge of the older person in everyday life, do you consider participant’s expression of “self-esteem” during the reminiscence session as:

<table>
<thead>
<tr>
<th></th>
<th>Beamish</th>
<th>Den Gamle By</th>
<th>Jamtli</th>
<th>Maihaugen</th>
<th>Hungarian Open Air Museum</th>
<th>In total</th>
<th>In %</th>
</tr>
</thead>
<tbody>
<tr>
<td>More than usual</td>
<td>21</td>
<td>16</td>
<td>6</td>
<td>1</td>
<td>3</td>
<td>9</td>
<td>55</td>
</tr>
<tr>
<td>Same as usual</td>
<td>11</td>
<td>14</td>
<td>11</td>
<td>13</td>
<td>8</td>
<td>57</td>
<td>48,7</td>
</tr>
<tr>
<td>Less than usual</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td>2</td>
<td>1,7</td>
</tr>
<tr>
<td>Don’t know/not sure</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td>3</td>
<td>2,6</td>
</tr>
</tbody>
</table>