



# Pop up Dementia Theatre



**Evaluation of the Pop Up Dementia Theatre – February 2016**

**BIG Lottery Report**



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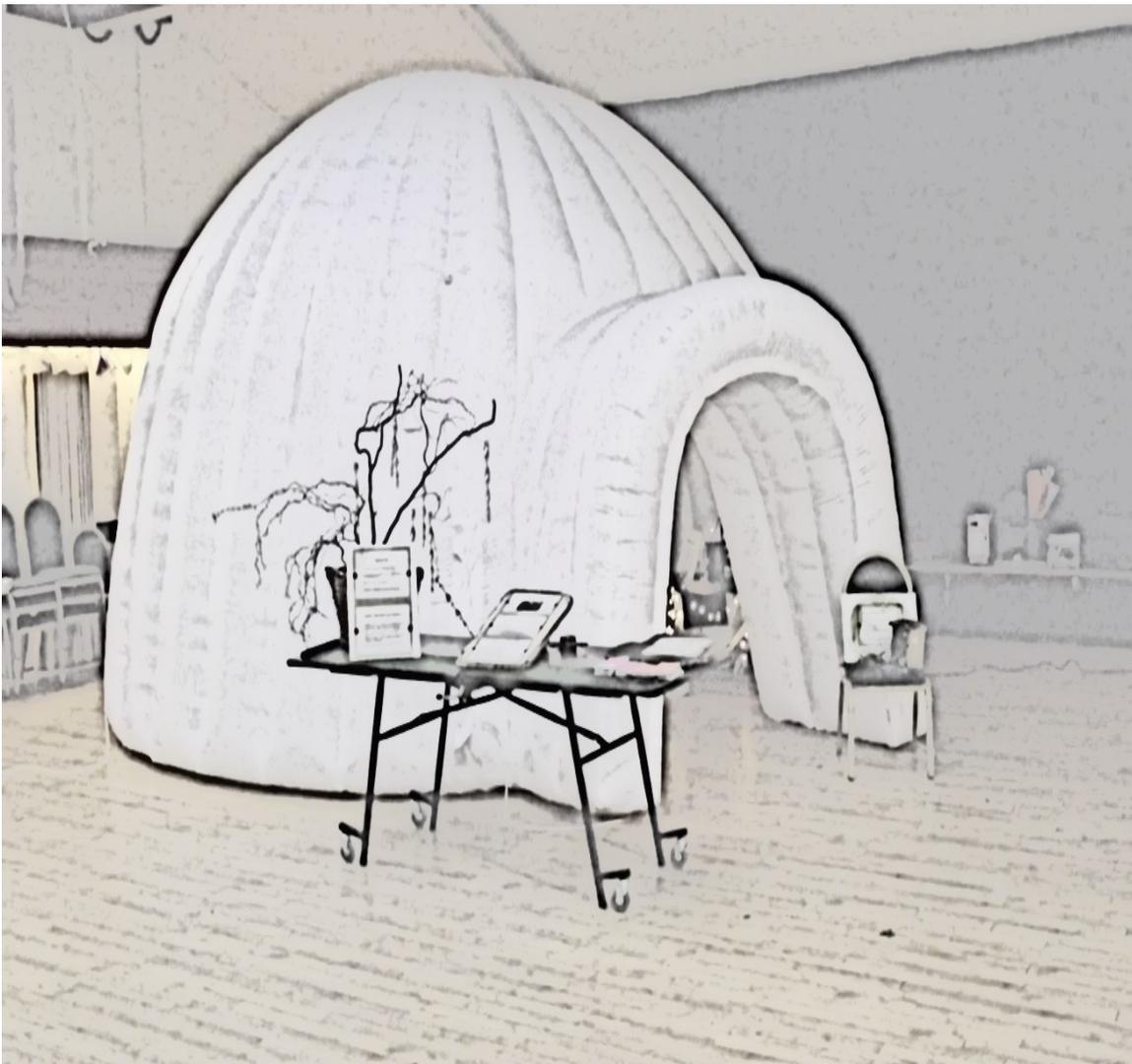
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## Background to the pop up dementia theatre

This document relates to a project run across Southampton, the Isle of Wight and Portsmouth aimed at improving the quality of life for individuals with dementia and their carers.

The project is a direct result of evidence based research into the effectiveness of sensory based stimulation in people with dementia undertaken by Dr Kim Brown of Nature Therapy CIC. This research was the result of her father contracting dementia and trying to find a way the family could continue to communicate with him outside of memory and language alone. The research was grounded in finding evidence based structured activities that impacted on the symptoms of dementia.

A meta-analysis of available research showed that sensory stimulation can improve communication, enhance quality of life, reduce social isolation, reduce agitation and aggression, improve sleep patterns, and lower the need for increasing medication. A reduction in aggression is particularly poignant for family carers who may be faced with this on a daily basis. It is known that aggression is a primary concern for some families and can result in police call outs, hospital admissions, and social care involvement. Longer term it can result in residential or health care provision.

Dr Brown tried each of the activities with her father to gauge his responses. This resulted in the prototype of the Haven programme of nature therapy in dementia care which was then shared much wider with other families who had a loved one affected by dementia.

The Haven Programme was originally piloted with ten families who had a significant other diagnosed with dementia or cognitive dysfunction. It was run as a three hour session, one day a week for 6 sessions on a family by family basis. Each session covered a different sense and fun activities were involved to help stimulate that sense to avoid sensory deprivation. Sensory deprivation is a form of torture called White Torture and evidence shows it can induce significant mental distress within as little as fifteen minutes - including disorientation and hallucinations.

Nature is used as the tool in the Haven programme for sensory experience. One advantage is nature is generally a familiar resource to the person with dementia. Ongoing costs in continuing with sensory communication through nature therapy are therefore relatively neutral as nature is free. Nature is something the majority of older people understand as they have spent much of their lives in the great outdoors, roaming freely in their childhoods and creating sensory memories as they explored the world through their senses. So, nature based activities involves less stress for them. In addition, nature is something the whole family can connect through as it is intergenerational.



The Haven programme is grounded in facilitating mindful sensory experiences for person with dementia. Mindfulness is about being present in the moment and is frequently advocated within mental health services to help with depression and anxiety. For those with dementia, the present moment is the focus of their dementia journey. As dementia progresses, there is often no choice but to fully experience the present moment through their senses and not necessarily through their minds.

Carers, family or friends, including children took part in the initial pilot. The findings showed it to be a practical and enjoyable method of helping participants understand a system of communicating with each other through nature. Laughter and enjoyment was evident, with many participants offering creative insights on how to evolve the programme. Social networking took place during the pilot and those resulting networks continue to sustain carers and people with dementia.

The most exciting outcome of the pilot was that all participants in a family were involved in co-designing the finished product. Families were actively engaged in the process and freely offered further ideas as they put into practice what they were learning each week and fed back their findings and insights. Thus, the Haven programme of nature therapy in dementia care was co-designed and developed by people with dementia and their carers/families. Families reported that nature therapy provided them with a structure to be able to connect and engage with their loved one through a new 'language'. That language is sensory speak.

The original programme was focused on the person with dementia however due to feedback from carers, the programme was adapted to ensure the carer was also at the heart of the programme. This was due to the reported benefits carers were finding in taking part. This included helping them feel relaxed, less stressed, have fun, meet new people and build social networks as well as improving understanding and communication with their loved one with dementia.

Many participants in the pilot and beyond have their own views on what they enjoyed and wanted to include in **their** programme, thus making nature therapy unique and individual to each family. There are gardening projects for older people but Nature Therapy is not simply about gardening, it is much wider and it has longer term sustainability for the family once they have learned the process of communicating in a different way. A way that does not require language, memory and logic.

Following the pilot, funding was secured from Portsmouth NHS Clinical Commissioning group to work with carers. The initial pilot had shown some evidence of a reduction in carer compassion fatigue; however the numbers were too small to draw any conclusive evidence. Compassion fatigue is the stage before burn out and can lead to debilitating effects for a carer.



This includes both mental and physical signs of severe stress such as sleeplessness, anxiety, depression, heart disease and ongoing stress has even been linked to the development of some cancers. All of which has a knock on effect to the individual they are caring for such as reduced communication, isolation, hospitalization – or in worse case scenarios safeguarding concerns.

The Isle of Wight NHS Clinical Commissioning Group also purchased the programme. Delivery was specifically focused on determining if nature therapy and dementia care impacted on compassion fatigue in carers.

Through the Haven programme families and carers in Portsmouth, and the Isle of Wight learned how to communicate with someone with dementia through sensory experiences using nature as a tool. They got to understand some of the science behind sensory communication and how the processing of this changes in dementia. They learned how to create their own unique nature therapy programme to trigger a positive internal state for the person with dementia and how to build nature into dementia friendly environments.

Outcomes from 126 participants showed a significant reduction in compassion fatigue in carers as measured by a reliable and validated compassion fatigue tool (ProQol) pre and post attendance. Carers reported the nature based activities were just as valuable for them in helping reduce stress. In a number of cases participants were at burn out level at the start of the programme with potential for the person with dementia to end up being crisis managed or hospitalized. The reduction in compassion fatigue in these individuals was important in terms of the commissioning funding bodies due to the high level of costs to the NHS and social care this would entail.

The target indicator was for 70% of participants to show a reduction in compassion fatigue but the results showed an achievement of 97%. The rationale given by participants was that as carers they now understood that challenging behaviours were not personally aimed at them. They also got out in the great outdoors either by themselves with their loved one. They felt the Haven programme gave them permission to take time out to get out and collect items to bring home. There is a body of evidence to show that time spent in nature can reduce stress.

Qualitative evaluation of the Haven programme showed participants felt that the knowledge and skills they gained on the programme improved the quality of life of the person they were caring for. They thought that the sleep patterns of the person with dementia improved, there was less agitation and aggression, and they reported evidence of enhanced engagement. They felt by attending the programme they had improved their relationship with the person or people they were caring for and this in turn improved the quality of life for the person with dementia.



Carers reported a high level of enjoyment for the person with dementia when they engaged in nature therapy. Carers found they could continue to communicate with individuals through sensory experiences long after memory and language had become fragile.

It was determined through the work with the two clinical commissioning groups that the Haven programme is suitable for all carers of people with a cognitive dysfunction, whatever their age, and is particularly useful for carers of individuals which have challenges in processing language. This includes people with Parkinson's, stroke induced memory loss, vascular dementia, Alzheimer's, as well as those with brain injury. From this work with older people Nature Therapy CIC has gone on to develop a similar programme for children with sensory processing disorders such as Autism.

The most important finding from the Haven Programme evaluation in relation to this report was that carers wanted the knowledge and skills they gained on the programme to be much wider shared. They felt it increased their sense of compassion, empathy and understanding of the person with the condition and that those with dementia would ultimately benefit from shared understanding. They felt communities, organisations, groups, families and individuals needed to know about the impact of sensory deprivation on those with dementia. Carers wanted the message of Think Sense to be disseminated on a national basis.

As carers wanted many more people to be made aware of the sensory deprivation that occurs with dementia in order to improve their quality of life Nature Therapy CIC explored creative ways of reaching a much wider audience with the Think Sense message. The Think Sense message advocates those interacting with someone with dementia to Think Sense before, during and after any interaction. This is the key message that carers felt should be relayed. The vehicle to deliver this message needed to be flexible, adaptable, fun, use experiential learning techniques and be able to reach larger numbers of people than the Haven programme alone. It also needed to synchronise with the Haven programme and provide a taster session, or prequel, to the full programme whilst standing alone in its own right.

Carers wanted others to have insight into what happens with the senses in dementia, why someone might behave the way they do, and more importantly what you could do to make a difference using something that was freely available.

Hence the pop up dementia theatre was conceived and born. It was felt a pop up theatre could reach out to the wider population, all of which might have contact with people with dementia, through being set up different venues. In this way, many more people could get a richer depth of understanding of the importance of sensory experiences for those with dementia, thereby improving their quality of life whilst reducing compassion fatigue in carers.





The pop up Theatre was designed to demonstrate that dementia is not just about fragmentation of the memory and language; it affects all the senses. We rely on our senses to process external information from the world around us, but with dementia, the ability to sense the world is diminished.

So, as dementia progresses, changes take place in how the world is seen, heard, smells, feels and tastes. This can lead to sensory deprivation resulting in extreme social isolation for the individual concerned. Sensory deprivation is also known as 'white torture' (the worst form of torture known to mankind) and can rapidly lead to aggression, agitation, hallucinations, depression withdrawal and poor sleep patterns. Research evidence shows that sensory based programmes, such as Nature Therapy, can and do make a positive impact on the distressing symptoms of sensory deprivation.

The pop up experience is intended to help participants understand that people with dementia are unable to process sensory information in the same way they did previously because of the changes taking place in the brain. However this is little known or understood, so the pop up furthers understanding of the changes that can and do take place. This includes not liking something they previously liked such as a genre of music. This is because of the changes that take place in sensory perception.

For example one lady was playing her father Jazz because he always enjoyed it as a younger man. However, he became more and more agitated when she played it to him. After applying the Think Sense technique she switched to nature sounds sound such as bird song.

The Big Lottery awarded the pop up a £10,000 grant in March 2015 through their Awards for All scheme. The grant enabled delivery for a one year period across Southampton, Isle of Wight and Portsmouth where the intention was to promote the message Think Sense. Being aware of the sensory changes that take place means participants can continue to communicate with someone with dementia long after language has become fragile. This different way of communicating means those with dementia are less likely to withdraw into a world of sensory deprivation and complete isolation. It can also help communities build better dementia friendly environments by taking into consideration all the senses and not just visual impact.

The pop up dementia theatre aimed to achieve an improvement in the quality of life for those with dementia and their carers through advocating the Think Sense message. This report examines if that aim was obtained.



## The pop up dementia theatre

The pop up theatre is a unique hands on sensory experience for participants wishing to understand more about the changes in sensory perception that take place with dementia. It is used to promote the Think Sense message which is about considering the sensory impact on the person with dementia. Seeing, feeling, tasting touching and smelling the world empathically through the lens, ears, nose, skin and mouth of a person with dementia.

The theatre itself is a 16 foot circular enclosed space that provides for a diminished visual environment. It can be erected indoors or out in relevant community spaces. Participants enter the theatre through a small corridor, where inside there are various sensory portals relating to each of the five senses. They work their way round each sensory portal gaining hands on experience of the sensory changes that take place alongside factual knowledge. They are also provided with ideas for nature based sensory experiences that are freely available alongside opportunities to try out some of the activities. Trained volunteers are on hand to help those using the sensory theatre to process their experiences and relate this to personal experiences. They are also able to provide basic onward advice and information.

## Overview of monitoring and evaluation

The following format was used to collect data for monitoring and evaluation of the pop up dementia theatre:



Target	Method of data collection
400 individuals experience sensory theatre	Sign in at entry to include contact details phone and email and if a direct carer of someone with dementia
100 of which are direct carers	Questions for carer: Sleep patterns for person with dementia on a scale of 1 to Pleasure from nature on a scale of 1 to Level of stress for carer on a scale of 1 to 10 Level of aggression and agitation on a scale of 1 to 10 Consent to further contact
Knowledge of sensory deprivation before theatre	True and false questions (pre)
Knowledge of sensory deprivation after theatre	Same true and false questions as above (post)
Follow up via email or phone 3 months later focusing on sleep patterns, improved pleasure, aggression and agitation, reduction in stress for carers	Contact details taken at entry  Survey monkey
6 focus groups	Semi structured focus group survey
Wishing tree to capture qualitative data	'leaves' to leave anonymous comments on

One of the challenges with only measuring set pre-established criteria such as self-measured carer stress level is that the richness and complexity of social and emotional life is not always captured. The pop up may ultimately be found to enhance resilience to compassion fatigue in carers – but it could also improve say, their social isolation. By only measuring set possible outcomes, we might just miss something equally valuable. Therefore, the evaluation took into account a wider capture of data. It was important the voices and views of the participants were heard above everything else to ensure their lived experiences came to life





## Outputs

The following two charts detail outputs from delivery of the programme up until February 2016:

Target	Method	Output (September 2015)
400 individuals experience sensory theatre	Sign in book at entry to include contact details phone and email and if a direct carer of someone with dementia – professional or family member.	A total of 702 participants attended at least one pop up dementia theatre session
100 of which are direct carers	Direct carer questions If a direct carer also ask Sleep patterns for person with dementia on a scale of 1 to 10 Pleasure from nature on a scale of 1 to 10 Level of stress for carer on a scale of 1 to 10 Level of aggression and agitation on a scale of 1 to 10 Consent to further contact	317 participants identified as direct carers of a family member  119 consented to further contact
Knowledge of sensory deprivation before theatre	True and false questions	689 completed forms
Knowledge of sensory deprivation after theatre	Same true and false questions as above	98%of participants showed improvement in their knowledge base
Follow up via email or phone 3 months later focusing on	Follow up via email, phone and survey monkey	38 follow ups
6 focus groups	Semi structured focus group survey	5 focus groups took place (n=23)
Wishing tree	Wishing tree with 'leaves' participants can leave anonymous comments on	Comments received



Input	Activity	Output
Pop up Dementia Theatre sessions	Total number of workshops	<p>A total of 24 pop up dementia theatre sessions were delivered in a 12 month period.</p> <p>This equates to approximately 30 attendees per pop up session.</p>
Hours	Total number of hours	<p>Each pop up dementia theatre session lasts an average of 8 hours. Each participant spends around 2 hours engaging with the pop up and the remaining time in discussion.</p> <p>The total number of hours dedicated to direct delivery of the pop up was 192 hours.</p> <p>The total number of hours dedicated to collection of resources, research, travel, set up, one to one support data collection, analysis and evaluation and follow up equated to a further 288 hours.</p> <p>The total number of hours amounts to 480 hours.</p>



## Results

The following results relate to the one year evaluation period of the pop up dementia theatre which ran until February 2016. The aim was to provide a maximum number of participants possible with a deeper understanding of the sensory changes that take place. The intention was to improve the quality of life for those with dementia by reducing extreme social isolation and distress caused by sensory deprivation. The pop intended to achieve this through engaging a minimum of 400 community based individuals, 100 of which were to be direct carers of people with dementia. The evaluation shows the target was easily achieved and almost doubled.

A monitoring tool and database was designed for this purpose. A copy of which can be found in the appendix of this document.

To date the pop up has been used at the following venues:

- Alzheimer's café
- Southampton General Hospital
- St Mary's hospital
- Portsmouth Hospital
- The Limes (Mental Health)
- Health Clinics
- Housing Complex
- Conferences
- Solent University
- Southampton University
- Portsmouth University
- School
- Community Centres
- Riverside health centre
- Fayres
- Southampton Community Hall

The range of venues included in delivery shows the diversity of the pop up and how it was adapted to a range of differing settings. The ability to be able to set up at any given venue is a valuable asset in taking the message of Think Sense out to the general population.



An expectation that individuals will take time out to come to a set place at a set time to learn more about sensory deprivation can be an unrealistic expectation, especially for carers. This range of settings achieved is a significant factor in obtaining a much higher footfall than would otherwise be possible if delivery was only at one set venue.

Targeting venues that are amenable to the Think Sense message, such as hospitals and Alzheimer's cafes, proved fruitful in reaching direct carers without too much additional effort on their part. This is an important consideration in terms of compassion fatigue where attending a programme at a community venue they might struggle to get to would mean the difference between attendance and non-attendance. Feedback has shown this to be a valued part of delivery, more so as it has also proved fruitful in recruiting carers onto the longer activities programme once they have had a taster session through the pop up.

The diversity of the pop up in being able to be set up at different venues also resulted in the Think Sense message reaching many more different populations than would otherwise be possible with a static venue. This ranges between delivery in an academic setting with professionals such as Professors, lecturers and researchers through to medical settings such as hospitals with professionals such as paramedics, nurses, operating assistants, and pharmacists. It also included family members, children with a loved one with dementia, people with dementia, professional carers and family carers. It has also included other interested parties such as health and social care commissioners, local authority workers, a High Sheriff, media representatives, journalists and other voluntary sector providers such as MIND and Age UK.

Delivery to the general population highlighted the very real fear many people have of dementia. As part of the focus group work, the majority of participants saw dementia as a negative condition that strips an individual of their individuality and all what they feel is precious to them i.e. memories. However, feedback suggests that the insights gained from the pop up experience about each of our senses having memories – often formed before we are born – led to a realization that dementia can give us permission to explore a sensory way of being once again.

The pop up experience does not adopt the position that dementia is a positive way of being, but the experience does appear to help negate some of the expressed fear of developing dementia. This fear is more apparent in family members, some of which are concerned there is a genetic component to the condition.



Part of the work in delivery of the pop up was to gain a wider perspective of the perceptions of children and young people on dementia to understand their needs in relation to this. A child friendly format was being used to collect data from children using the Write and Draw technique to understand their needs in relation to helping a family member with dementia.

This demonstrated that children tend to believe that dementia can be treated by a Doctor but they can feel completely distressed by their loved one's challenging behaviours. This relates primarily to agitation and aggression. The children in the evaluation felt hurt when a loved family member did not remember them. As one young person put it *first she forgot my name, then my mums name, and now she doesn't even know her own name*. Overall the child participants demonstrated great compassion towards those with dementia but they were unsure what they could do to do to help the person with dementia and other family members who might be upset. One child reported being confused about her mixed feelings of grief and relief after her grandmother passed away following a period of dementia.

To date the pop up has accommodated **702** individuals - well above the target of 400. The database shows that **98%** of those participants significantly improved their knowledge of sensory deprivation and dementia. Of those individuals, **317** identified themselves as direct carers of someone with dementia. This is also above the target of 100 carers. Interestingly many of those in the caring professions, such as nurses, also had a dual role in caring for a family member which replicates findings from the Haven programme evaluation.

Immediate Qualitative feedback has been wholeheartedly positive. These are examples are taken direct from the database of anonymous comments left on the wishing tree:

*Fantastic experience, very informative and eye opening!*

*Has made me very aware of dementia and the way it affects people's senses. Thank you :-)*

*The dementia pop-up theatre is an interesting and revealing insight into the senses and how they are affected by dementia.*

*It is hard to understand this simply by reading and talking about it and the pop-up helps us to understand better.*

*Very interesting display, learnt some valuable things regarding senses, enjoyed the experience.*

*Very informative and simply presented. Learnt a lot about effects on those with dementia and can understand their experiences and how to support them.*



*Very interesting to learn how peoples senses are affected by dementia.*

*Very interesting and a good idea, learnt a lot.*

*Very enlightening, extremely interesting.*

*Peaceful, inspiring, thought provoking.*

*Count your blessings - Touch, taste, smell, sight and sound.*

*Very, very interesting would never of thought about this, thank you.*

*Loved it! Keep up the great work.*

*Very interesting and informative. Useful techniques that anyone can use.*

*Really useful and thought provoking, thank you.*

*A very insightful experience, definitely recommend to others.*

*Really enjoyed session, learnt a great deal.*

*Taking knowledge outside the box.*

*Fantastic experience and insight in to the world of someone dealing with dementia. Increased my knowledge and awareness and enabled me to take away small/large difference that I and others can make.*

*A great practical and visual method of developing awareness of dementia. Eye opening experience to what people with dementia go through.*

*Nature can provide our senses with so much and evoke a huge range of emotions, memories and thoughts.*

*Very interesting workshop it helped me to overcome some of my communication barriers and be more open to new experiences. Learning about dementia is also very important.*

*Thank you for a very thought provoking and stimulating workshop.*

*Natural prompts - Free - Nostalgic - Refreshing*

*There is still so much we don't know.*

*A great way to experience dementia. Thank you, looking forward to the 5 week course.*

*Thank you for helping me to understand dementia and the signs of dementia.*



*Finding the right smell to evoke a positive memory for someone could be a really good way to make them feel happy.*

*Nature has a positive impact on every aspect of our life.*

*Smell - I could die without smell! It brings so many memories to the surface.*

*Taste - I struggle to produce the same taste as my grandmothers chicken sauce ( she died with Alzheimer's) but I cannot, I still try.*

*Thinking about how smells can evoke memories, recognising how impacting white noise is.*

*I was surprised by how many different factors could be affected by dementia and how nature can help.*

*A great interactive experience :-) Nice to learn how the different senses are affected and can be changed.*

*Really informative - very helpful to experience interactive activities, really helped understanding.*

*Really thought provoking, good for relaxation.*

*Being deaf and wearing hearing aids, I found the experience really difficult as it was very noisy. I normally avoid these situations as it overtakes your thinking and am unable to cope or process, I guess this is what people with dementia feel, when for e.g. the Hoover is on in the house*

*Very enjoyable, all nurses/carers, actually everyone should experience this, so valuable.*

*Beautiful way of learning, a feeling we cannot ignore when looking at our loved ones.*

*Enjoyable and inspiring.*

*Perceptual changes - just like that blue/black/white/gold dress!*

*I enjoyed the experience, thank you. It has really helped my thinking, as my uncle seems to be showing signs - e.g. not listening to his previously favourite music, thank you. About myself too, getting older :-)*

*Very informative & simply presented to learn. Experiences enable future understanding of the condition. Enclosed environment offers area to focus on the sensory experience being presented.*

These comments have not been filtered but lifted direct in a block from the database. It can be seen that comments are generally centred on gaining an insight into the world of those with dementia and an increased understanding and empathy towards what they might be experiencing. The hands on interactive format of experiential learning was also a valued part of the pop up experience. Participants reported enjoyment alongside an increased knowledge.



Follow up took place via telephone of participants who identified themselves as personal carers to see if attendance at the pop up dementia theatre made a difference for the person they were caring for. The differences being accounted for were any changes in sleep patterns, agitation and aggressive behaviours, and signs of pleasure.

The significant factor in this follow up was a reported reduction in agitation and aggression immediately following the pop up dementia experience when carers were trying to implement the Think Sense message. This reduction is in keeping with the evidence base that suggests that agitation and aggression can be linked to negative sensory experiences for a person with a dementia. The reported reduction in agitation and aggression is indicative of an improved quality of life for the person with dementia. Carers explained they felt this reduction in negative behaviours was primarily due to the fact that following the pop up experience they were more fully aware that aggression and agitation can be linked to negative sensory experiences. They had tried to embed the Think Sense message into their daily care routine. Some found it easier than others but all those followed up had at least tried with the majority maintaining this approach.

For example, one gentleman was reported as becoming increasingly agitated which often led on to him being aggressive towards his wife. His wife was becoming more fearful of him and her stress levels were increasing because of this and heading towards compassion fatigue. And burn out. Through the Think Sense message she started to understand the pattern of his challenging behaviours were related to washing and bathing. So, she used the Think Sense technique and looked at the situation from his perspective. She found that by using the touch technique she learned as part of the pop up experience to desensitize him, that she could slowly introduce him to being touched and then move on to washing. She reported feeling connected to her husband once again and no longer saw washing him as a chore filled with fear and dread.

Follow up feedback from general participants was also undertaken. The purpose was to see how the knowledge and skills gained from the pop up dementia theatre in relation to dementia friendly environments had been used. This revealed the experience being used in a variety of different ways:



A team of ambulance paramedics piloting improving the smell inside their ambulances to make it more comforting i.e. use of natural calming smells such as lavender

An operating department using materials to improve the anesthetic room experience from a visual perspective i.e. looking up towards the ceiling

Nurses bringing in natural resources such as hanging plants to residential homes and long stay hospital wards to green up the area and make it less clinical

Commissioning officer looking at how they can include nature and Think Sense in their commissioning contracts with nursing homes

An interior design lecturer using the knowledge gained from the pop up to encourage their students to Think Sense when designing areas for those with dementia to make them dementia friendly for every sense.

A psychologist working with carers who is now helping them understand more about compassion fatigue and how nature and sensory experiences can help them just as much as the person they are caring for.

A residential home manager who has greened up the home and is now teaching care assistants to Think Sense

An academic researcher inspired to research smell and dementia

A shop owner who wants to ensure the layout of their shop incorporates Think Sense to make it a more dementia friendly environment – and to ensure staff are Think Sense aware.

A voluntary sector organisation already working with people with dementia using the Think Sense message for work with families.

A teacher who wants to use the pop up in her school to help children with experience of a family member with dementia



It is noted that some of these examples have the potential to benefit a much wider group than people than those with dementia alone.

It can be seen from these examples that the message of the pop up dementia theatre to Think Sense is clearly snowballing. Whilst 702 people have had direct experience of the pop up, the evidence that the message is spreading much wider than participants alone as it snowballs across communities is persuasive. On one hand the challenge is trying to record and contain monitoring of this spread for reporting purposes but on the other hand the wider the message is shared, the better it is for improving the quality of life for those with dementia.

In terms of calculating the secondary impact of the pop up on extended contacts of participants, a modest approach would be to assume that each participant shared information with around 5 other people. This would mean secondary impact extended out to a further 3,510 people.

**Due to lottery funding there are literally thousands more individuals who have a better understanding of how sensory deprivation impacts on a person with dementia through the key message of Think Sense. This is thousands of people that now have the potential to improve the quality of life for someone with dementia through enlightened compassionate understanding.**



Feedback shows information was shared by participants with colleagues, family members and friends. Some replicated nature based activities with their children and grandchildren so they would have an activity to do with their loved one with dementia. This is a finding consistent with the Haven Evaluation. This means new generations of children are growing with a far better understanding of the impact of dementia on sensory perception and what they might do to help.

The Think Sense message shared with colleagues led to adaptations to their work environment to enhance dementia friendly environments. This included hanging plants, starting nature based activities sessions, exploring smells around the environment, and making soundscapes (maps) of sounds. This latter action has shown to be especially important in ward based environments where sounds such as continuous alarms can be distressing to people with dementia, but staff are often unaware as they are desensitized to certain types of noise.

Those contacted explained that the impact of the pop up meant they were far more empathic to those with dementia. They reported trying to understand negative behaviours through the lens of what the sensory problem was before taking any other action. They reported being Think Sense aware.

It is worth noting there was a small amount of feedback which suggested the experience was upsetting for some participants. This primarily focused on those who had already suffered the loss of a loved one with dementia *'I wish I knew all of this when my mum was still alive as I would have been more understanding. I thought she was just playing up and sometimes I got irritated with her because of it. Now I know I should have looked more carefully at what she might have been sensing'*.

Notwithstanding, despite their upset, these were the participants that felt it was even more imperative that the message of Think Sense was shared. The focus in this type of scenario was to help the individual focus on what they did do and not what they didn't do.

## Quality of Life

Measurement of quality of life for people with dementia is a challenging concept for a variety of reasons not least to do with the processing of information required to complete survey formats. Measurement in relation to the pop up is through ascertaining impact on quality of life through the lens of the carer.



This is the person in direct contact with the individual on a daily basis. Therefore measurement relied on asking them to use observation to determine any changes in sleep patterns, agitation and aggression and signs of pleasure and enjoyment and then score those items on a scale on one to ten (likert scale).

The responses suggest the major impact of the Think Sense technique was on episodes of agitation and aggression which carers reported as being been the most welcome difference. This reduction in episodes of agitation and aggression, or in escalation of same, is the primary finding in terms of what difference attending the pop up made to the lives of carers and the person they were caring for.

This reduction in aggression equates to the reduction in stress (compassion fatigue) for carers that was also reported. Caring for a loved one on a 24 hour basis that has the potential to become violent is mentally and physically exhausting. Not only that, there is the possibility that severe harm might occur to the carer. One lady reported moving into a separate bedroom and barricading the door at night as she was so frightened of her husband. There is also the possibility of severe harm occurring to the person with dementia. The same lady reported her husband going outside to get an axe to try and hack through her closed bedroom door. The gentleman in question had a rare form of dementia whereby he was hallucinating and believed he was back in the war and was trying to save his wife from the enemy who was intent on harming her. She explained that when he did eventually get to her he made her sit in silence and not move for some hours so as not to alert the enemy to their whereabouts. She spent those hours terrified of what might happen next. This case study highlights that more research is needed to look at how the Think Sense message could benefit those with this specific type of dementia, Lewy Body, and their carers.

Whereas the Haven programme evaluation found the most significant and overarching difference reported was that of an **increase in communication** between carers and people with dementia. The Think Sense message which developed from the Haven programme is demonstrating a more specific difference which is that increased communication has the potential to impact quite majorly on the quality of life for someone with dementia and their carer **by reducing episodes and scale of agitation and alongside a decrease in the distressing symptoms of carer compassion fatigue.**

A poignant factor is the shift in carers from being a carer that does something **to** a person with dementia that might be a causative factor for an aggressive episode to being a carer that does something **with** the person with dementia. That is, the carer is alongside sharing sensory experiences with them and seeing, feeling, smelling, hearing and tasting the world through their perspective. This is empathy in action; it is compassionate and sensitive care that can lead to less health and social care crisis intervention, police call outs, and a reduction in safeguarding concerns.



## Summary

We experience and learn about the world through our senses from the moment of birth. Our senses, sight, smell, hearing, touch and taste connect our minds with the world around us. Sensory deprivation is a known form of torture that can induce paranoia, agitation, loss of circadian rhythms, aggression, hallucinations, learned helplessness and depression. All expressions of distress observable in people with dementia.

During the later stages of dementia, although there may be some challenges with reasoning and language areas of the brain, individuals still retain a sense of touch, taste, smell, vision and hearing. Sensory stimulation for people with dementia can trigger bygone memories where they recollect sensory experiences from long ago. Our senses have their own memories thus we have for example a gustatory memory or a touch memory and although changes in processing sensory experiences may take place, sensory memories remain intact for longer.

Findings from this evaluation demonstrates that those with a dementia can benefit from carers being aware that activities that stimulate the senses can lead to the increased socialization.

Boredom and frustration are two most common causes of challenging behaviours and aggression and agitation are primary reasons for crisis intervention, hospitalization and entering the care system as well as for police call outs. The evidence thus far from the interim evaluation of the dementia theatre is suggesting that insights gained from participation in the pop up experience through applying the Think Sense technique leads to fewer episodes of agitation and aggression and when they do occur they are not at a level where police, health or social care are involved.

This evaluation of the pop up has demonstrated an improvement in stress levels for carers suggesting the programme can help them build resilience. Gaining a greater understanding of other ways to communicate with someone with dementia has been found to be helpful in achieving this.

Carers reported a change in attitude from perceiving behaviour as challenging to getting alongside the individual to try and experience the world from their perspective. This can only be of benefit to people with dementia.

The findings show there was less social isolation for people with dementia as a result of enhanced sensory activities involving nature and as a consequence more expressions of enjoyment and pleasure. Less isolation means an improved quality of life.

Dementia friendly environments have been enhanced through improved knowledge and understanding that sensory experiences are a vital part of the environment for someone with dementia. This is an environment where all the senses are recognised and stimulated in a variety of differing situations.





***The pop up dementia theatre is a trademarked resource. The intention is to continue to disseminate the Think Sense message throughout Hampshire by offering an accredited training and support package to 50 Think Sense Ambassadors***

## Appendix

### Please complete before entry to the Pop Up dementia Theatre

Venue/date

Number

Are you caring for someone with dementia? Yes  
No

If yes, are you caring for a member of your family or a friend ? Yes  
No

*(\* If you are a family carer, please help us further by completing overleaf)*

If yes, is care work what you do for a living? Yes  
No

If no – do you have someone in your family with dementia? Yes  
No

Can you say what interests you in taking part in the pop up dementia theatre today?

We would like to find out how dementia theatre may improve the lives of people with dementia, if you are happy for us to contact you in a few weeks to complete a short survey, please leave your contact details below. We will not pass your details to any other organisation or try to sell you anything.

My Name:

My preferred method of contact is *(please write your address, telephone or email below)*:

Thank you so much for taking part in the pop up dementia theatre session and we hope your experience today will benefit people with dementia into the future.



## Before pop up experience

If you are a carer for someone with dementia please rate the following statements

The general quality of sleep for the person I care for is:

(Poor) 1 2 3 4 5 6 7 8 9 10 (Good)

The person I care for experiences pleasure from being amongst nature:

(Never) 1 2 3 4 5 6 7 8 9 10 (Daily)

As a carer I would say my level of stress is:

(High) 1 2 3 4 5 6 7 8 9 10 (None)

The person I care for can become agitated and/or aggressive

(Never) 1 2 3 4 5 6 7 8 9 10 (Daily)

Thank you so much for your help – Nature Therapy CIC



Before the Pop Up Dementia Theatre Experience

Please mark the following statements as true or false

- Dementia is only about memory loss
- Touch increases your blood pressure
- The smell of peppermint can make you angry
- Smell is one of the last senses to change with dementia
- Smell does not impact on our memories
- Sun downing is when someone with dementia falls asleep
- The most sensitive part of our body is our back
- Dementia can make us more sensitive to heat
- Someone with dementia does not like being touched
- Someone with dementia always recognises their image in a mirror
- Taste is our strongest sense
- Putting food on white plates is important
- Sensory experiences through nature can lead to aggression



## Immediately after pop up experience

Please mark the following statements as true or false

- Dementia is only about memory loss
- Touch increases your blood pressure
- The smell of peppermint can make you angry
- Smell is one of the last senses to change with dementia
- Smell does not impact on our memories
- Sun downing is when someone with dementia falls asleep
- The most sensitive part of our body is our back
- Dementia can make us more sensitive to heat
- Someone with dementia does not like being touched
- Someone with dementia always recognises their own image in a mirror
- Taste is our strongest sense
- Putting food on white plates is important
- Sensory experiences through nature can lead to aggression

The most fascinating fact about our senses and dementia I have learned today is .....

The pop up Dementia Theatre experience could be improved by .....



## Three months after pop up experience

Date of pop up experience

Date of survey

Name

Number

Method of contact

If you are a carer for someone with dementia please rate the following statements

The general quality of sleep for the person I care for is:

(Poor) 1 2 3 4 5 6 7 8 9 10 (Good)

The person I care for experiences pleasure from being amongst nature:

(Never) 1 2 3 4 5 6 7 8 9 10 (Daily)

As a carer I would say my level of stress is:

(High) 1 2 3 4 5 6 7 8 9 10 (None)

The person I care for can become agitated and/or aggressive

(Never) 1 2 3 4 5 6 7 8 9 10 (Daily)

Thank you so much for your help – Nature Therapy CIC if you would like a copy of the final report then please let us know.

