

# Think Dementia, Think Sensory

**Agnes Houston MBE**  
**Fellowship Year 2016**  
**Medical and Health**

WINSTON  
CHURCHILL  
MEMORIAL  
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My time in Ireland and Canada was made possible by the wonderful people I met along the way. I would like to acknowledge the incredible input from people living with Dementia; their thoughts, experiences and recommendations were invaluable<sup>1</sup>.

The Dementia Working Groups in Ireland and Canada were extremely helpful and I would not have been able to meet with as many people as I did, if it were not for their time and effort.

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A special Thank You goes to the following people who helped to host us:

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- Elaine Wiseman – Northern Ontario Dementia Working Group.
- Phyllis Fehr – Ontario Dementia Working Group.
- Ron Beleno – RB33 Joining the Dots.

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- Life Changes Trust.
- Outside the Box.
- HammondCare.
- E-CRED (Edinburgh Centre for Research in the Experience of Dementia).

The final Thank You must go to my daughter, Donna. She accompanied me throughout all my Churchill Fellowship travels and organised the practical arrangements. She monitored my health and wellbeing as we travelled and prompted me to rest and recuperate when I needed it. Without the constant support from Donna I would not have been able to undertake this Fellowship.

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<sup>1</sup> Additional names and organisations can be found in my itineraries.

## About Me

My background is in Nursing and I was a manager in a Chiropractic Practice for several years. I cared for my Father who had Alzheimer's and Vascular Dementia. In 2006, at the age of 57, I was diagnosed with early onset, early stage Dementia of the Alzheimer type.



Agnes Houston

Not long after my diagnosis I started experiencing sensory challenges. First were the visual disturbances, then changes to my sense of smell and hearing. It wasn't mentioned in any of the literature I was given and not discussed by any of the clinical practitioners I was seeing. I quickly came to the realisation that there was little to no support or information around the sensory changes that I was experiencing as part of my Dementia. These experiences have since influenced my work.

I passionately campaign for better information and resources at a local, national and international level. I have been fortunate to work alongside some wonderfully inspiring people who I have met through many different organisations.

In the year of my diagnosis I was introduced to the Scottish Dementia Working Group (SDWG) by the founding member and then chair, James McKillop. I have since chaired this group and have remained an active committee member of over 10 years. I am also actively involved in the following groups:

- Current board member of Dementia Alliance International.
- An exchange fellow of Edinburgh University.
- Member of the Dementia Engagement and Empowerment Group (DEEP).
- Director of Dementia Friendly Communities Social Enterprise.
- Founding member and previous Vice Chair of the European Working Group of People with Dementia.
- Founding member of Scottish Dementia Alumni.

Through these platforms I have continued to campaign for improvements in Dementia care, particularly surrounding sensory issues. In 2013, I was awarded a lifetime achievement award from Alzheimer Scotland. In 2015, I created a booklet and DVD on 'Dementia and Sensory Challenges'. Later

that year I was awarded an MBE for my work in the field of Dementia.

In 2016, I was awarded a Churchill Fellowship which enabled me to travel to Ireland and Canada. I explored best practice relating to Dementia and sensory challenges. My findings inspired me and I hope to share these with others in the UK.

## Summary

As part of my Churchill Fellowship I travelled to Ireland and Canada to speak with people within the Dementia field. I wanted to explore any work relating to sensory changes and Dementia;

- What awareness is there of sensory changes with Dementia?
- What is being done to address the associated challenges?
- What can the UK learn from Ireland and Canada?

I met with people across a wide range of backgrounds including people living with Dementia, clinicians and societies. I gathered anecdotal evidence, clinical studies and academic research. I was fortunate enough to visit innovative care providers who are leading the way in combining medical care with holistic health and wellbeing. The case studies included in this report are created from my notes, observations and reflections from these visits.

### Findings

I have developed 6 case studies that showcase innovation and offer valuable learning to the UK. My first two case studies are from Ireland. They outline two different approaches in reducing the impact of sensory challenges and are led by healthcare teams in Clonskeagh Hospital, St. James Hospital and Connolly Hospital.

The second two case studies outline different approaches to care provision. 'Memory and Company' provides a country-club style wellbeing centre for people with memory loss. Schlegel Villages offer inclusive community-based residential care.

The last two case studies are examples of collaborative multi-disciplinary approaches to Dementia care, research and policy. 'Baycrest Health Sciences' are a multi-functional facility focussing on brain health and ageing. The Alzheimer's Societies of Canada, Ontario and Toronto share office space so I could speak to all three during my Fellowship visits.

I also spoke to many people living with Dementia who echoed my own thoughts and experiences. As I spoke about the sensory changes many people felt that I was describing what they had been living with but were struggling to express. The findings validated their experiences and gave a context to what was happening in their own lives.

Along with the case studies I also observed the following good practice:

- Thoughtful design.
- Recognition of the ageing process.
- Similarities with other neurological diagnoses.
- Opportunities for choice.

## **Recommendations**

I conclude my Fellowship report with a series of recommendations:

- Implement a multi-disciplinary approach to Dementia diagnosis and care.
- Raise awareness and conduct research around hyperacusis and the 'Uncomfortable Loudness Levels' test.
- Raise awareness around the neurological and physiological changes associated with Dementia.
- Develop a UK Sensory Pathway Guide that brings together relevant advice for people experiencing changes.
- Think Sensory, Ask Sensory; recognise the sensory changes and be proactive in addressing them.
- Provision of specialist Dementia Care such as self-management teams and specialist Nurses.

## Introduction

### Background

*"Dementia is a common condition. Your risk of developing dementia increases as you get older, and the condition usually occurs in people over the age of 65.*

*Dementia is a syndrome (a group of related symptoms) associated with an ongoing decline of the brain and its abilities. This includes problems with:*

- *Memory Loss.*
- *Thinking Speed.*
- *Mental Agility.*
- *Language.*
- *Understanding.*
- *Judgement."*<sup>2</sup>

### Sensory Changes and Challenges

Dementia is different for everyone. Along with some of the symptoms listed above, I and many other people, also experience sensory changes and these bring along another set of challenges.

Your tastes change. You no longer enjoy your favourite food and drinks. Food doesn't taste the same. The texture feels different and off-putting. Eating and drinking can become very difficult when you no longer enjoy it.

Sounds and noise can distress you in a way they didn't before. This is called Hyperacusis.<sup>3</sup> Day-to-day noise can become physically unbearable. I can no longer tolerate sounds such as a running shower, a boiling kettle or a flushing toilet. Public places such as restaurants, hotels and shopping centres have become very challenging for me.

Changes in sense of smell often have people thinking that they can smell things such as burning, food that has gone off and cat urine. These

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<sup>2</sup> NHS Choices. What is Dementia? <http://www.nhs.uk/Conditions/dementia-guide/Pages/about-dementia.aspx> [June 2017]

<sup>3</sup> Hyperacusis is the intolerance to everyday noises. It can cause distress, anxiety and extreme pain. NHS Choices. What is Hyperacusis? <http://www.nhs.uk/Conditions/hyperacusis/Pages/Introduction.aspx> [June 2017]



'phantom smells' can be very confusing; I can no longer trust my own sense of smell.

These changes don't happen in isolation to one another. Experiencing multiple sensory changes can be extremely distressing. The symptoms can also change, so you may react to different triggers at different times of the day. For me, they intensify at the end of a day when I become tired. This also means that my physical and emotional responses can vary. I am often left feeling drained and disorientated because of these sensory challenges as they impact on all aspects of my life.

### **Sensory Changes and Challenges Film**

This film accompanies a booklet that I created, which was launched in 2015. It documents the real-life experiences of 24 people from across the UK and Europe, who live with Dementia. Follow this link to hear about the sensory experiences of others as well as the visual disturbances I've experienced.

[https://www.youtube.com/watch?v=U\\_L2107EweQ](https://www.youtube.com/watch?v=U_L2107EweQ)



YouTube Clip of 'Dementia and Sensory Challenges'

## **Dementia Care in Scotland**

In 2007 the Scottish Government identified Dementia as a priority. It has since developed two Scottish Dementia Strategies (2010-2013, 2013-2016) and has just launched the third: Scotland's National Dementia Strategy 2017-2020.<sup>4</sup>

Dementia care in Scotland is delivered around two models that have been developed by Alzheimer Scotland.

### **5 Pillars Model of Post Diagnostic Support**

*"Alzheimer Scotland's Five Pillars Model of Post Diagnostic Support shows the five key elements which are essential to supporting a person after their diagnosis."*<sup>5</sup>

- Supporting Community Connections.
- Peer Support.
- Planning for Future Care.
- Understanding the Illness and Managing the Symptoms.
- Planning for Future Decision Making.

The 5 Pillar model is upheld by The Scottish Government PDS (post diagnostic support) Guarantee. This provides a minimum of one-year post diagnostic support from a named person. However, only people diagnosed after 1 April 2013 are eligible to receive this guarantee.

### **8 Pillars Model of Community Support**

*"This 8 Pillar Model of Community Support sets out a comprehensive and evidence-based approach to the integrated support of people with dementia living at home or a homely setting during the moderate to severe stages of the illness."*<sup>6</sup>

- Dementia Practice Coordinator.
- Support for Carers.
- Personalised Support.
- Community Connections.
- Environment.

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<sup>4</sup> Alzheimer Scotland. Scotland's National Dementia Strategy 2017-2020.

[http://www.alzscot.org/assets/0002/6035/Third\\_Dementia\\_Strategy.pdf](http://www.alzscot.org/assets/0002/6035/Third_Dementia_Strategy.pdf) [June 2017]

<sup>5</sup> Alzheimer Scotland. 5 Pillar Model. [http://www.alzscot.org/campaigning/five\\_pillars](http://www.alzscot.org/campaigning/five_pillars) [June 2017]

<sup>6</sup> Alzheimer Scotland. 8 Pillar Model.

[http://www.alzscot.org/campaigning/eight\\_pillars\\_model\\_of\\_community\\_support](http://www.alzscot.org/campaigning/eight_pillars_model_of_community_support) [June 2017]

- Mental Health Care and Treatment.
- General Health care and Treatment.
- Therapeutic Interventions to tackle symptoms of the illness.

These two models along with Scotland's Dementia Strategy 2017-2020 lay the foundations for personalised support with greater efficacy. However, there remains a gap. My research leads me to believe that sensory changes and challenges continue to be under-recognised at a clinical and strategic level. Feedback from people living with Dementia shows there is little to no easily accessible literature or support offered around these changes.

However, an article in *The Journal of Dementia Care* "Demonstrating the Sensory Changes of Dementia" <sup>7</sup> brings together the current academic literature, along with the information set out in my booklet "Dementia and Sensory Challenges; Dementia can be more than Memory" <sup>8</sup>. From this information, they developed a workshop that used experiential learning to demonstrate these sensory changes to professional care staff. The aim was to bring about a change in practice for those that participated. They concluded that the hearing and vision sections of the training were relatively successful but that there was still a way to go for the other senses; taste, smell and touch.

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<sup>7</sup> Banham, M., & Soares, L. (2017). Demonstrating the Sensory Changes of Dementia. *The Journal of Dementia Care*, 26-29.

<sup>8</sup> Houston, A (2015). Dementia and Sensory Changes. <http://www.lifechangestrust.org.uk/our-publications>

## **Aims and Objectives**

This Fellowship aims to raise awareness of these sensory issues and will look at ways in which it is being recognised, understood and supported in other countries.

### **Fellowship Aims:**

- Gain experience and understanding of how sensory changes are recognised and supported in Ireland and Canada.
- Raise awareness of the neurological sensory changes that can accompany Dementia.
- Raise awareness of the impact of the physiological ageing process on people living with Dementia.
- Identify, share and implement practical solutions and approaches that diminish the effect of sensory changes for people living with Dementia.
- Start the process of creating a UK Sensory Pathway/Guide.

### **Fellowship Objectives:**

- Meet with individuals, organisations and professionals who have experience within the field of Dementia or sensory changes.
- Gather evidence of good practice that supports people living with dementia who experience sensory changes.
- Share the knowledge gained from this Fellowship with people living with dementia, carers, colleagues, practitioners and policy makers in the UK.

## **The Approach**

During my visits to Ireland and Canada I met with people from over 30 organisations. I wanted to meet with people who could share a wide range of knowledge from several different perspectives:

- People Living with Dementia (PLWD) and their Carers.
- Professional Care Providers.
- Universities and Research Departments.
- Hospitals, specifically Audiologists and Ophthalmologists.
- Alzheimer Societies and Groups.

The information I gathered from discussions, observations, and presentations was loosely structured around several key themes:

### **Awareness of Sensory Changes**

- Are these issues well-known and openly discussed?
- Do people who experience these changes feel listened to?
- Are professionals acknowledging these changes?

### **Addressing the Challenges**

- Is there current clinical studies and research?
- Is there a Dementia Sensory Pathway Guide being used?
- What is working well for PLWD?
- How are these changes being implemented?

### **Learning for the United Kingdom**

- What could be replicated in the UK, and How?
- Practical changes that could enhance the lives of PLWD?
- What would need to be included in a UK Sensory Pathway Guide?

## **Report Overview**

In this report, I will share the stories and anecdotes of people living with Dementia. Case Studies will provide examples of best practice that left me feeling inspired and hopeful. Information gathered from professionals and clinical practitioners will set these sensory challenges in a neurological and physiological context. I hope these findings will form the beginning of a UK sensory guide.

## Findings

### **Case Study 1; Practical Solutions and Dementia-friendly resources**

#### **Memory Harbour Resource Centre, Clonskeagh Hospital**

The Memory Harbour Resource Centre is run by occupational therapists who understand the practical challenges that can be associated with Dementia and other types of memory loss.



Memory Harbour

I was told that in Ireland, the numbers of people who have Dementia and live at home are much higher than people who have Dementia and live in a care setting. Understanding this context helped me to see how crucial this service is to people living with Dementia and their carers. The team at Memory Harbour aim to find practical solutions to everyday challenges; they listen to the issues people experience and work towards resolving these.

#### **My Observations and Reflections**

In one room, they have a library of resources. They have sourced these resources from all over the world and offer people the opportunity to try them out in their own home.



Some of the simple, practical resources available to try in your own home.

The sensory room creates a lovely relaxing space that can be used to engage the senses or soothe and relax them. Coloured lighting, projectors and soothing sounds can be personalised to whoever is using the space; whether it is people who experience memory loss, or for their carers. I was delighted to see my booklet framed on the wall; sending a powerful message about the importance of caring for the senses.



The Sensory Room

## **Case Study 2; Creating Sensory-Friendly Spaces.**

### **St. James Hospital and Connolly Hospital, Dublin.**

During my first day in Ireland I visited two Accident and Emergency Departments at St. James Hospital and Connolly Hospital. In both hospitals staff within the Accident and Emergency departments had recognised the impact of sensory overload for people who had been admitted. In an already heightened state of anxiety these additional stressors (bright lights, repetitive noises, loud voices) often resulted in people becoming increasingly distressed and agitated. This sometimes meant that people were admitted overnight for something that could be treated relatively easily and quickly.

The staff looked at creating treatment bays that reduced these sensory stressors to enable people to be assessed and treated with minimal distress.

### **My Observations and Reflections**

In the first treatment bay I visited, staff had fitted controllable sensory lighting that could change colour to suit the moods of patients and reduce the sensory impact. The bay was free of clutter and the medical equipment was kept out of the line of sight. I also noted that the toilet was directly opposite the bay, avoiding any further distress or confusion.

The second hospital has a very similar set-up although they were unable to install the lighting system due to financial restrictions. However, they did install noise-reducing screens along with the privacy curtains. While this did not stop the usual hospital noises it certainly dampened and softened them.

Staff spoke to me about trying to install soothing music. I explained that this would have to be through headphones (to avoid overload with other sounds) and must suit the tastes of the patient. We discussed the challenges around this but I was enthused that they were trying to innovate and use current technology effectively.

I was also told that there had been discussions around staff training to better equip them to identify the symptoms of Dementia. This would enable them to treat the patient more effectively with less distress. I was impressed by the work done in both hospitals – these changes will greatly benefit not only people with Dementia but others who are also affected by sensory challenges such as those with autism or post-traumatic stress disorders.

### **Case Study 3: A different approach to Day-Care provision.**

#### **'Memory and Company' – Toronto, Canada.**



The founders of Memory and Company showing Donna and I around their centre.

'Memory and Company' is a wellness health club. It is open to all, although it is first and foremost a judgement-free space for people living with memory loss through Dementia, Alzheimer's, Parkinson's, stroke and brain injury.

Due to the environment and opportunities available, the club tends to attract a younger group of members compared to the other day-care programmes available in Canada.

Formal and informal carers are welcome to attend the club with members through their 'Better Together' programme. The club focusses on offering holistic wellbeing through a range of opportunities such as music and art therapies, spa and personal care, pet and plant care. Movies and sports events are shown in the theatre space while cooking and baking can be done in the communal kitchen space.

Memory and Company are in partnership with universities and hospitals to further the research and improve the quality of life for people with memory loss.

#### **My observations and Reflections**

I was so impressed; it looked like a high range members club. As soon as I walked in I could sense the 'feel-good' atmosphere. There was a sense of freedom that made me feel welcomed and relaxed.

The varied rooms stimulated playfulness, provided opportunities for reminiscence and in the music room my spirits soared. There was no clinical hospital feel to it, everything felt very luxurious and pampering.



The language being used was giving me a feeling of wellness and safety. It made me feel respected and supported.

The staff could and would bathe and shave members to relieve and free the care-partners of caring tasks. This removed a lot of stress and provided opportunities for people to be together without the associated 'caring' roles.

The kitchen area was open plan and well thought out. The space was open so two walkers could safely be there side by side. The corners were rounded, things were at good heights – small details making the space more accessible for all who wished to use it.

Food was colourful and interesting. Snacks were out for people to try when they wished. There was water and juice in clear glass containers available at all times. Safety measures had been added appropriately but positive risk taking was encouraged. Sensors were installed on the fridges and on the cutlery drawers meaning that their members could use the space freely without restriction, while maintaining certain safety elements. I was impressed at this thoughtfulness – it wasn't a big added expense as the sensors could be picked up on the high street.

The entertainment room was a dream. Again, there was no institutional feeling. It felt luxurious; being spoilt made me feel extremely special. It was like going to a select upmarket premier showing at a movie theatre. The screen was connected to the internet so it could be used for a range of screenings; sports, movies, cultural events. The games room also had lots to offer for lots of different interests.

There was an outdoor space with a barbecue. In the summer, the door is open which creates more freedom and choice for members.

It is such a contrast to the day-care facilities we have in the UK. I would love to be able to be a member here. Many people I spoke to said that their loved ones were thriving in this environment, I can see why.



Memory and Company's music room – complete with records and instruments.

## **Case Study 4; A different approach to Residential Care**

### **Schlegel Villages**

Schlegel Villages offer residential living that combines quality long-term care with retirement villages across Ontario, Canada.

The design of the space creates a 'village' feel with recognisable places such as Town Square and Main Street. The communities also provide a Town Hall, café and Community Centre.

Integration with the larger surrounding communities is essential to the ethos of Schlegel Villages. *"Age-friendly community living surrounds all of our Villages; they're close to churches, schools, parks, services and shopping centres, and they're easily accessed by public transit. We promote community involvement, inviting neighbours from the surrounding communities to participate in social, recreational and fitness programs alongside the residents of each Village. Our Community Connections program also offers unique opportunities to people living in the local community to engage in Village life."*<sup>9</sup>



Welcoming and accessible signage.

### **My Observations and Reflections**

#### **The Village of Wentworth Heights – Hamilton, Ontario**

As I entered the facility I was impressed with the design and sense of space. There was a village feel with a library, a shop and a post office, a pub and a Town Hall, where I would be speaking. I noticed that they had good signage, the staff had happy smiling faces and were acknowledging all the residents by their first name.



Wentworth Heights, Schlegel Village – a warm, welcoming environment.

<sup>9</sup> Schlegel Village. About Us. <http://schlegelvillages.com/about> [June 2017]

We went to an area where residents were engaged in flower arranging, then another area where residents were sitting round a table doing crafts. I was introduced to the newest member of the class – their new pet budgie. One lady had her iPad and talked of the iPad classes she attended. She talked of her love of music and how she uses her iPad to listen to her favourites. iPads were attached to tables in the café for residents to try and see if they liked them.



Easily accessible iPads for all residents.

There was so much to do. The café area was well used; a group of residents were playing cards and laughing. The Chapel area was all set up for a meeting; they had a talking stick made by the men from another Schlegel Village.

I was invited to deliver a talk in their Town hall on Dementia and Sensory Challenges – 'Dementia can be more than memory'. I saw the residents walking together along Main Street chatting to each other – as you would in any outside community.

The Education Training Team; Dr Al Powers and Jessica Luh Kim prioritise staff training and development. Staff wear polo shirts and t-shirts rather than formal uniforms found in traditional institutional settings.

### **The Village of Tansley Wood – Burlington, Ontario**

I also visited Tansley Woods - another Schlegel Village. Although the decor is familiar, the residents give it a different feel. I liked knowing that just outside the village you have a retirement community who use the facilities inside Tansley Woods and some who would eventually want more support and would choose to move into Tansley Woods as permanent residents.

The team members were smiling and talked of being valued, I liked this team code of ethics. Their holistic approach to caring and how the team called everyone by name; it had a family feel to it. I liked the feel of openness. The residents talked of their experiences of being free to do what they liked and some had recently been on holiday. This was arranged by a staff member which included flights, a hotel stay and even joining in at a Casino.

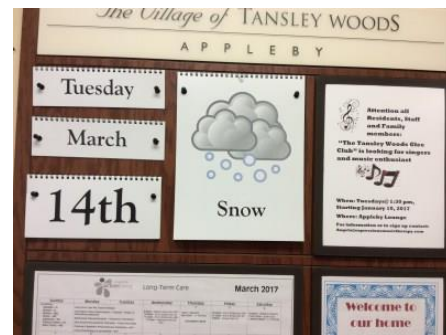
Again, I saw iPads dotted around this village as well. They also have iPad classes to support people to make the most of the technology. There were lots of interesting little places for you to enjoy; a shop on site or you can put your name down to visit shops in the local community.

There are kinesiologists who will develop a personal exercise plan and help to keep you motivated and healthy. One of rooms that I liked was the woodwork area where residents made things for their games room, presents and gifts that were sold at fetes.

In the long term residential areas, a young man was engaging everyone in a music quiz using technology on the big TV screen, one resident was knitting as well as joining in.

You could see from the notice board what the weather was, what activities were on and when some of the residents were arranging the flowers that were displayed throughout the village.

Food is an important part of Schlegel Village life. I liked the way the hospitality staff talked about the importance of presentation as well as choice. The quality of the food was so good the outside community use the restaurant within Tansley Wood Village.



Signage with words and images.

I felt so welcome. I wondered what makes me like the Schlegel Village so much. I liked their philosophy, their vision and the execution. I liked the positive language used. It was the feeling that this holistic model of care helped you to get the most from your life. To live life to the fullest. Your life, your way. You had a choice in what to do; a place to be quiet or to join in when you wanted to. The staff liked to talk about their work and their joy and satisfaction was obvious. Everything looked to run smoothly, but I know the work behind the scenes that goes on to make this possible. They treated elders with dignity and respect, and as having wisdom.

I believe I could thrive and still enjoy a good life living somewhere like this. I was not surprised to hear that there is a large waiting list and a big extension being built to accommodate this waiting list. I believe there are many aspects that we would be able to learn from and replicate back in the UK.

## **Case Study 5; Understanding Dementia and the Ageing Brain**

### **Baycrest Health Sciences**

Baycrest is a multi-functional facility in Toronto, Canada. It combines older peoples residential living, healthcare, research and education. They have a focus on furthering knowledge of brain health and ageing.



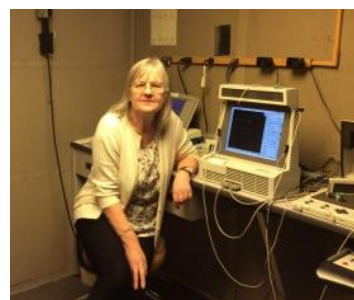
Meeting the Baycrest Team.

All their work encompasses their four values; Compassion, Advocacy, Respect and Excellence. They have a strong vision *"We will transform the experience of aging through leading innovations in brain health, wellness promotion, and approaches to care that enrich the lives of older adults."*

<sup>10</sup>

### **My Observations and Reflections**

I met with Marilyn Reed, Audiology Practice Advisor for Baycrest Health Sciences. I was particularly interested in her work around hearing-loss and the ageing brain – she shared some of her findings in her presentation 'Brain Deafness'. Some of the common complaints she was coming across *"I can't hear in background noise"*, *"I can hear people talking, but I can't make out the words"* – were all very familiar to me. She explained that age-related changes to inner ear, central auditory systems and cognitive ability can all impact on an individual's sense of hearing. She drew on research by her colleagues to show the crucial link between hearing, memory and cognitive function. Memory and comprehension suffer when the quality of the sound input is reduced, increasing listening effort.



Visiting Baycrest's audiology department.

<sup>10</sup> Baycrest. Our Story. <http://www.baycrest.org/about/our-story/mission-vision-values/> [June 2017]

Reed went on to discuss the implications of hearing-loss and hearing difficulty for people with a Dementia diagnosis. She outlined simple strategies to improve communication with people who have hearing-loss and Dementia.

In her summary of recommendations, she states that good management of hearing loss in patients with Dementia could, among others, potentially slow the rate of cognitive decline and should incorporate 'compensatory behavioural strategies' rather than focussing on hearing-aids and assistive technologies alone.

I feel that Marilyn Reed's work has important implications for people who live with Dementia and experience sensory challenges – such as hyperacusis. I found the term 'Brain Deafness' very helpful and simply describes what I and many other people live with day-to-day.



## **Case Study 6; Being Positive and Proactive**

### **Canadian Alzheimer's Societies**

As part of my Fellowship I met with three Alzheimer's Societies: Alzheimer Society of Toronto, Alzheimer Society of Ontario and the Alzheimer Society of Canada – who all share office space.



Meeting the staff of The Alzheimer's Societies.

I was impressed by the good design of their office space – good signage and appropriate décor. It was informative and felt welcoming without overwhelming my senses.

It was a good time to visit Canada as they have just committed to developing a national Strategy and have recently launched their framework proposal.<sup>11</sup> I will be following this development with interest.

### **My Observations and Reflections**

During my time with the Alzheimer's Societies I was struck by the positive attitude and behaviours of the staff and organisations. They were incredibly open-minded and responsive to the ideas I was sharing with them.

I felt that they had a strong commitment to developing and progressing their own practice. I was impressed at how proactive the societies were; a team meeting was immediately set up to look at how to take forward and implement some of the ideas we had shared.

Another aspect that stood out was their multi-disciplinary approach. All societies worked alongside clinical specialists such as audiologists, ophthalmologists and psychologists. This approach of collaborative working is an area where I think there is important learning for us in the UK.

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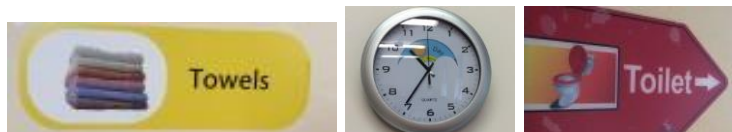
<sup>11</sup> Alzheimer Society of Canada. Canada's National Dementia Strategy. <http://www.alzheimer.ca/en/Get-involved/Advocacy/National-dementia-strategy> [June 2017].

## Best Practice

**Design** - Good design of physical space was a key element of my findings. In each of my case studies I could identify well thought out spaces. This includes:

- useful signage that uses clear fonts alongside images and symbols.
- spaces that limits additional background noise such as traffic.

Purpose built spaces such as Memory and Company and the Schlegel Villages had managed to create 'sensory-friendly' spaces.



Examples of the good signage I found at The Memory Harbour, Ireland.

**Recognition of the impact of the ageing process** – The organisations I visited in Canada all recognised the impact of the ageing brain on the senses. I found that information about these changes were more widely available than back in the UK. Sensory changes were recognised and talked about as part of the ageing process meaning that better provisions were offered.

**Similarities in Sensory Challenges with other diagnoses** – I spoke with many people who discussed similar sensory challenges that accompanied other diagnoses such as Autism Spectrum Disorders (ASD), Post-Traumatic Stress Disorder (PTSD) and Brain Injury. A future UK Sensory Pathway Guide could offer useful information to many people in the UK – not only people who experience sensory challenges due to Dementia.

**Opportunities for Choice** – Across all the 'care' settings I visited, one of their main priorities was to offer their members and residents choices. It appeared, to me, that opportunities for maximising choice and freedom had been in-built into programmes and was recognised as being as important as medical care and safety. Freedom to choose upheld individuals human rights – building respect and understanding between people living with Dementia, their carers and associated professionals.

## Sense Specific Findings

**Sight** - Neurological Visual Impairments. The eyes are healthy and can see perfectly but the brain cannot interpret and understand the information. The term 'Brain Blindness' will be a useful one when speaking with people about these visual challenges.



**Hearing** - In Ireland I discovered the audiological test relating to Hyperacusis and tinnitus; the ULL Test 'Uncomfortable Loudness Levels Test'. In Canada, I heard that this test was offered, as standard, within a normal consultation. The link between hearing loss and Dementia is well documented. A study by Dr. Frank Lin showed that people with severe hearing loss are up to five times more likely to develop dementia as people without any hearing loss<sup>12</sup>. Like 'brain blindness', people are hearing sounds and noises but the brain is unable to interpret these into something recognisable; 'brain deafness'.

**Taste** – It was brought to my attention that eating is one of the few acts that we can do that engages with all the senses. Many of the chefs I spoke with talked about how they approach preparing food by taking the senses into consideration. Texture is crucial, particularly for people who have identified swallow issues. An Australian chef, Peter-Morgan-Jones offers wonderful advice about preparing foods for people with Dementia. He is also Executive Chef for HammondCare; an innovative health and aged care provider in Australia. I think his work will be relevant across many diagnoses for people who experience sensory changes. The book 'Don't give me eggs that bounce – 118 cracking recipes for people with Alzheimer's'<sup>13</sup> goes into detail about many issues relating to sense of taste and eating.

**Touch** – While visiting 'Memory and Company' and the 'Schlegel Villages' I was aware that staff and carers were aware of changes to someone's sense of touch and were looking for signs that this was happening. A commonly reported change can be when someone was once very tactile, now no longer liked to be touched, often causing distress.

**Smell** – Small changes can make big differences. It also sends a strong message to people living with sensory changes – it creates a safe and welcoming atmosphere. Baycrest designated itself as scent-free. While this might be difficult to implement in public spaces, it is a low-cost option for organisations that are working alongside people with sensory changes.



Baycrest taking a scent-free approach.

<sup>12</sup> Action on Hearing Loss. Hearing and Dementia. <https://www.actiononhearingloss.org.uk/your-hearing/about-deafness-and-hearing-loss/hearing-loss-and-dementia.aspx> [June 2017]

<sup>13</sup> Morgan-Jones et al., 2014. Don't Give Me Eggs that Bounce.

## Conclusions

In the months after my travels I have been reflecting on my Fellowship and feel very positive about it. It confirmed my initial thoughts regarding the lack of information and resources around sensory issues. I gathered anecdotal and clinical evidence that supports the thinking that Dementia support should not only focus on cognitive decline but take into consideration the neurological, physiological and sensory aspects too.

I saw similar gaps in Ireland and Canada around these issues however there is a real drive to move their understanding and resources forward. I met with Government representatives from both countries who are committed to addressing these issues at a strategic level.

Canada provided me with some fantastic case studies demonstrating holistic wellbeing approaches that created sensory friendly caring environments.

In Ireland, I met with audiologists and learned about the ULL (Uncomfortable Loudness Levels) test which can support people with Hyperacusis. I explored this further during my time in Canada.

I feel that in the UK, particularly in Scotland, we must raise awareness of the sensory aspect of Dementia and other Neurological diagnoses. I was impressed at the multi-disciplinary approach I witnessed in Canada. Increased collaborative working between ophthalmologists, audiologists and psychologists would provide greater knowledge and information that is currently not available through mainstream Dementia care.

## Recommendations

- **A multi-disciplinary approach:** Dementia diagnosis and subsequent care could be improved by embedding a collaborative approach. Combining professionals from neurology, audiology, ophthalmology and occupational therapy could offer individuals greater access to support that is already provided but unavailable through the current Dementia care pathways. I believe this could also offer earlier diagnosis and greater information for people who are experiencing sensory changes.
- **ULL Test:** Increase awareness regarding the ULL test (Uncomfortable Loudness Level test). This is currently available through Audiology and often offered during a fitting for hearing aids or other assistive technologies. This should also be offered to people who experience sensory changes due to Dementia; where hyperacusis may be more of an issue than hearing loss for people with an early-onset or an early-stage diagnosis.
- **Neurological and Physiological:** A cultural change is required within the UK. Dementia diagnosis and care currently focuses on cognitive decline such a memory loss. This is undoubtedly crucial for the ongoing care for people living with Dementia. However, if there was more research and information relating to the other lesser known symptoms of Dementia people would be able to access a more holistic, well-being focussed care package – like those that I witnessed in Canada.
- **A UK Sensory Pathway:** A UK guide is required for people who experience these sensory changes. This would bring together all the current information and support into one easily accessible place. The impact of this guide could be far reaching and relevant to people who have diagnosis of conditions other than Dementia; autism and brain injury among others.
- **Think Sensory, Ask Sensory:** As well as encouraging medical professionals to think about the sensory aspect of Dementia I also recommend that sensory questions and prompts are included in routine assessments. A sensory baseline to allow the changes to be tracked and monitored would be very beneficial, particularly for sight and hearing. This could help create a clearer picture of an individual's

symptoms, particularly those that may not be identified through the current assessments such as the Mini Mental State Examination (MMSE).

- **Specialist Dementia Care:** The need for flexible, person-centred Dementia care is great; support and care is needed that works for people all along the spectrum of Dementia. A Self-Management Dementia Team who would be able to support people to live their lives with Dementia in a way they choose. This would enable people to cope with the day to day challenges and continue to thrive in their own homes. Alongside this team I would recommend specialist Dementia Nurses who could offer additional support when people experience change or crisis.

### **Dissemination and Implementation**

I intend to share this report, my findings and recommendations with my current contacts and networks. This will enable me to have a UK-wide reach. I will also share this report with the individuals and organisations I met through my fellowship in Ireland and Canada. My hope is that this will help to forge new international working relationships that can shape exciting innovation in the UK Dementia scene.

I will also be working alongside specific organisations with a view to implement my recommendations, including the creation of a UK Sensory Pathway Guide;

- **Vision** – I will be working with the College of Optometrists to pull together key optometry and ophthalmology information. They have developed extensive training for optometrists working with people with Dementia. In April, I attended their event at the Houses of Parliament for the Prevalence of Visual Impairment in Dementia (ProVIDe) project where I spoke about my findings and my recommendations.
- **Taste and Smell** – I will be meeting with groups across Scotland to gain information about real life experiences of changes to the sense of taste and smell. These have been scheduled for late summer and early autumn. This will culminate in a short booklet with helpful hints, tips and solutions. I will be carrying out this phase of work alongside Outside the Box who offer development support throughout Scotland.

- **Hearing** – In June I presented to the British Society of Audiology at their Annual Conference. This is the leading UK scientific forum for clinicians and researchers who have an interest in hearing, balance and tinnitus. I will be following up with the contacts I made at this event and I have agreed to be a key note speaker on Dementia at upcoming audiology conferences.
- **Design** – To share my Fellowship findings and progress Dementia friendly design I will be working alongside Dr. Julie Christie and Prof. Mary Marshall OBE who are part of HammondCare’s Dementia Centre UK team. The team consists of Dementia specialists, Senior Consultants, Architects and Chartered Engineers.
- **Edinburgh Centre for Research on the Experience of Dementia (ECRED)** – I will share my Fellowship findings with this interdisciplinary group consisting of people living with Dementia, researchers, practitioners and organisations.
- **Sonas apc** – In May I attended the Sonas conference as a key note speaker where I shared the findings of my Fellowship and discussed how we could implement my recommendations.

## Appendices

### **Ireland Itinerary – December 2016**

<b>Dates</b>	<b>Location</b>	<b>Individuals and Organisations</b>
4/12/16	Arrive in Dublin	
5/12/16	St. James Hospital, Dublin	Natalie Cole. DemPath – Dementia Care Pathway.
	Connolly Hospital, Blanchardstown	Susan O'Reilly. Journal Club. Dementia Friendly Environment Design Group.
6/12/16	University Hospital, Dublin	Roulla Katiri, Chief Audiologist
7/12/16	Dublin	Sinead Grennan CEO, Sonas Apc
	Dublin	Helen Brennan, Chair European Working Group.
8/12/16	Ashling Hotel Dublin	Pat McLoughlin CEO, The Alzheimer Society of Ireland. Irish Dementia Working Group. Global Brain Health Initiative Fellows.
	Avila Carmelite Centre, Dublin	The Alzheimer Café
9/12/16	Avila Carmelite Centre, Dublin	Sonas Apc
12/12/16	Memory Harbour Resource Centre, Clonskeagh Hospital, Dublin.	Catherine Daley. Living Well with Dementia Project.
14/12/16	Leinster House, Dail Eireann	Tina Leonard, Head of Policy Alzheimer Ireland. All-Party Oireachtas Group on Dementia.

15/12/16	Galway	Heather Gately Dare to DREAM
16/12/16	University of Galway	Life Course and Society Faculty Carmel Geoghan. Helen Brennan Professor Eamon O'Shea
18/12/16	Return to Scotland	

### **Canada Itinerary – March 2017**

<b>Date</b>	<b>Location</b>	<b>Individuals and Organisations</b>
28/2/17	Arrive in Canada	
1/3/17	Toronto, Ontario	Mary Schultz Alzheimer Society of Canada / AS of Toronto / AS of Ontario
2/3/17	Toronto, Ontario	Memory and Company
4/3/17 & 5/3/17	Mars University, Toronto	Dementia Hack
7/3/17	Baycrest Health Sciences Hospital, Toronto	Marilyn Reed - Audiology Practice Advisor Dr Kelly Murphy, Clinical Neuropsychologist - Neuropsychology and Positive Health.
8/3/17	Toronto University	Psychology Department. Kathy Pichora Fuller Audiologist -Adults Development and Ageing
9/3/17	Toronto Rehabilitation Institute	Prof. Kathy McGilton - Nursing Prof. Elizabeth Banon - Speech Pathology, Prof Jenny Campos - Psychology, Prof. Emirati Jack Williams - Health Epidemiology. Science and Research Department.
13/3/17	Hamilton, Ontario	Schlegel Village, Wentworth Heights – Al Powers, Jessica Luh Kim and Phyllis Fehr

14/3/17	Burlington, Ontario	Schlegel Village, Tansley Wood
15/3/17	Travel to Waterloo	Lisa Loiselle, MAREP
16/3/17	Waterloo	Cultural Exchange, Research Institute for Ageing
20/3/17	Lakehead University, Thunder Bay	Elaine Wiseman - Centre for Education and Research on Ageing and Health (CERAH). Northern Ontario Dementia Advisory Group.
21/3/17	Thunder Bay	North West Local Health Integration Network.
	Lakehead University, Thunder Bay	Dr Michael Bedard – Department of Health and Social Sciences. Director of the Centre for Research on Safe Driving. Betty DeKraker - Audiologist.
	Thunder Bay	Community Care Access Centres
22/3/17	Thunder Bay	Alzheimer Society Thunder Bay
		St. Joseph's Hospital
		Thunder Bay Regional Health Sciences Centre
24/3/17	Return to Scotland	