Dementia Keeping Connected

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Winston Churchill Fellowship Report 2016
https://dementiakeepingconnected.wordpress.com/
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Over one hundred people with dementia, their families, carers and staff who inspired me throughout my travels.

Finally, the Winston Churchill Memorial Trust for believing in me and giving me the opportunity of a lifetime. I will be eternally grateful.

I dedicate this fellowship report to Abigail Richmond, my grandmother who had dementia and who has inspired me to improve the experience of people living with dementia.
I am the National Improvement Lead for Focus on Dementia at the Scottish Government. Focus on Dementia is a partnership improvement project which was established to support the implementation of Scotland’s second dementia strategy. My role involves supporting health and social care partnerships across Scotland to improve the quality of post diagnostic support and to test out a new model of care co-ordination in the community (the 8 Pillars Model). This model, developed by Alzheimer Scotland, aims to support people with moderate to severe dementia to stay well at home and resilient for as long as possible, and remain connected to their communities, avoiding crises, such as admission to hospital and out of hours call-outs. Like many other people, I have had family experience of dementia and I now combine my passion with my professional experience including an MBA (change management focus) and improvement skills to facilitate change in dementia care.

I have presented both in the UK and internationally and have supported the work of the G7 for dementia and the EU Joint Action for Dementia. At a G7 event in Edinburgh in 2014 I had the opportunity to hear a flavour of the work being undertaken in Japan and the USA and to meet leaders at the cutting edge of improving dementia care. These countries are working with other countries across the world to find innovative solutions for improving the quality of care for people with dementia, to invest in research and ultimately to find a cure. However, we know that many people with dementia can live well and, given the right support and care, can remain resilient and stay connected to their communities. It is this aspect of care quality which has been the focus of my Winston Churchill Fellowship and has taken me to Japan and the USA in 2015 to compare practice with the UK in order to share insights and ultimately inform UK practice.
Foreword: Expect the Unexpected

When I met with the Winston Churchill Memorial Trust, Winston Churchill Fellows of 2014 and prospective Fellows of 2015, two phrases stuck in my mind: ‘Expect the Unexpected’ and ‘This will be an opportunity of a life time’. I never expected to be so blown away…

On this symbolic year of the 50th anniversary of the death of Winston Churchill, I was privileged to have the opportunity to compare dementia practice between Japan and the USA and understand more about the history and cultures which underpin these inspiring countries.

During my travels I have been in two earthquakes, one typhoon and one volcano eruption. I have been welcomed by the Mayor of Uji City, been supported by the British Embassy and many translators and met amazing colleagues, now dear friends, who have helped me with my itinerary, travel arrangements and local traditions, and after three weeks in Japan I have finally mastered how to use chop sticks!

I am eternally grateful to the Winston Churchill Memorial Trust for this amazing opportunity and to family, friends and colleagues for their support throughout my travels.

During my travels I kept a blog to enable me to capture experiences in the moment and share them with colleagues, family and friends at home. See blog report: https://dementiakeepingconnected.wordpress.com/
Executive Summary

This report sets out the findings of a Winston Churchill Fellowship to Japan and the USA to compare west with east in how these countries are supporting people with dementia to live well and stay connected to their communities.

Never before has dementia received such a high profile. Through the G7 collaboration Japan, the USA and the UK are working together with other countries across the world to find innovative solutions for improving the quality of care for people with dementia, to invest in research and ultimately to find a cure.

During this Fellowship I have heard about the national plans and strategies for dementia and have seen how these plans are being implemented in practice. I have met with key organisations and individuals at the cutting edge of improving dementia care and have been privileged to meet people living with dementia and their families and heard first-hand what keeps them resilient and positive.

The thematic analysis contained in this report provides a flavour of these rich experiences and compares the policy context for dementia in Japan, the USA and Scotland. It also explores the uniqueness of these countries, and how a human rights approach, culture and leadership play important roles in reducing stigma and supporting people to live well and stay connected to their communities. The analysis draws on the Alzheimer Scotland 8 Pillars Model which is currently being tested in Scotland, paying particular attention to two of the pillars: Personalised Support and Community Connections.

The case studies contained within the report are based on my extensive notes which I took during my travels and provide insights into my feelings and experiences in the moment. This information also informed the blog which I kept during my travels.

On returning home I have disseminated my findings widely and have had the opportunity to reflect on my experiences with my local community, local business leaders and locality planning group. Nationally I have shared my findings with the Scottish Government and Alzheimer Scotland colleagues, and will this year share my work more widely at forthcoming international conferences and events.

Through engaging with the local community I have now established a Steering Group and together we are taking forward Dementia Friendly Prestwick in the town where I live. This exciting development is involving people with dementia and carers to promote an inclusive culture which respects the human rights of people with dementia and their carers, supporting them to stay connected to their communities.

“A man does what he must in spite of personal consequences in spite of obstacles and dangers and pressures – and that is the basis of all human morality.”
– Winston S Churchill
1. Introduction

This report sets out the findings from an inspirational trip to Japan and the USA through a Winston Churchill Fellowship in 2015, to understand how these countries are supporting people with dementia and their family carers to be resilient and live well in their communities.

2. Background

2.1 Why Dementia?

There are 800,000 people living with dementia in the UK and by 2050 Britain is expected to have around 1.7 million people with dementia. There are 670,000 carers of people with dementia in the UK. Dementia costs the UK £26.3 billion per year. Family carers of people with dementia save the UK £11 billion per year. In a survey by Alzheimer’s Society, 34% of people with dementia are not living as well as they could and do not feel a part of the community. In the UK an estimated 40% of people with dementia live in some form of institutional care and this is higher than in other countries (Alzheimer’s Association).

With an ageing population and the numbers of people living with dementia set to double, never before has there been such an emphasis on this condition. The UK, like other countries across the world, has a firm commitment to improving the quality of dementia care and support.

2.2 Comparing Contexts

2.2.1 Scotland

Dementia has been a national priority in Scotland since 2007 and Scotland is now on its second National Dementia Strategy. Underpinning this strategy is a human rights based approach and a focus on care quality. A key commitment within the strategy includes co-ordinated care and support in the community for people with dementia and their carers. Dialogue events are now underway to inform the next strategy due to be published in Autumn 2016. Scotland is also leading the EU Joint Action on dementia on behalf of the UK for the next three years. The Scottish Government are committed to supporting the implementation of dementia policy into practice and as such Focus on Dementia, a national partnership improvement programme, was established to support the second dementia strategy. One key element of this programme is working with partners to test the Alzheimer Scotland 8 Pillars Model, a model to support care co-ordination in the community for people at the moderate to severe stage of their dementia.

2.3 Sharing Practice: Japan and the USA

Through the G7 collaboration, launched by David Cameron as part of the Prime Minister’s challenge in 2012, Japan, the USA and the UK are working together with other countries across the world to find innovative solutions for improving the quality of care for people with dementia, to invest in research and ultimately to find a cure.

However, we know that many people with dementia can live well and, given the right support and care, can remain resilient and stay connected to their communities. It is this aspect of care quality which has been the focus of this Winston Churchill Fellowship.

I was keen to visit both Japan and the USA due to the demographics of dementia and exciting developments taking place in these countries in order to compare how the different
cultures and other factors including leadership may impact on the care quality in these countries.

2.3.1 Japan

Japan has experienced an unprecedented increase in its elderly population with the proportion of elderly people reaching 23.3% of the total population (2011). This elderly population rate was estimated to reach 33.4% in 2015 and 39.9% in 2060. In 2015 the estimated number of people with dementia was 3.45 million with an expected increase to 4.70 million by 2025. Japan, like the UK, has experienced difficulties with early diagnosis and co-ordination between health and social care services, and commissioned an international comparative study which has since informed a ‘Five Year Plan for Promotion of Measures Against Dementia (Orange Plan)’ (Nakanishi M, Nakashima T, 2014).

![Photograph of ladies dancing in Ueno Park, Tokyo](image1)

2.3.2 USA

According to the Alzheimer’s Association, 5.3 million Americans have Alzheimer’s disease. Of the 5.3 million, an estimated 5.1 million people are age 65 and older, and approximately 200,000 individuals are under age 65 (younger-onset Alzheimer’s). Diagnosis rates, transitions between care settings and the size and diversity of the country all add to the complexities (Alzheimer’s Association USA).

![Photograph taken at the Lincoln Memorial Reflecting Pool, Washington](image2)
3. Approach and Methods

3.1 Aim

The aim of this Fellowship is to learn about the quality of care co-ordination in the community for people with dementia in Japan and the USA and to compare this with how Scotland is supporting people with dementia.

3.2 Objectives

- To learn about the dementia policies and strategies in Japan and the USA and see how these are being implemented in practice.
- To learn how people with dementia and their carers are being supported to stay well within their own homes (or a homely setting) for as long as possible, avoiding crises including admission to hospital and emergency call-outs, and how people are enabled to stay connected to their community, including dementia friendly communities.
- To hear about innovations and examples of good practice in dementia care and support in the community and how these are being shared.
- To understand how different cultures can impact on the care quality of and support provided for people with dementia and carers.

In advance of my trip, I contacted policy leads at the Scottish Government, other Winston Churchill Fellows and colleagues involved in the G7, the EU Joint Action on Dementia and World Dementia Council members. This supported me when contacting leading agencies and individuals in Japan and the USA who were invaluable in connecting me with leaders of dementia care and innovative examples of practice. They also supported me to identify translators in Japan and helped with advice before and during my trip.

4. Findings and Case Studies

The thematic analysis below compares the policy context for dementia in Japan, the USA and Scotland. The case studies included in this report explore the uniqueness of these countries and how culture and leadership play an important role in reducing stigma and supporting people to live well and stay connected to their communities. The analysis draws on the Alzheimer Scotland 8 Pillars Model which is currently being tested in Scotland, paying particular attention to the Personalised Support and Community Connection pillars.

4.1 Organisations visited

4.1.1 Japan

During my trip to Japan I had the opportunity to visit nine day centres and group homes and met over 100 people with dementia, their family carers, health and social care staff, policy makers, researchers and businesses. I had meetings with professors at the cutting edge of dementia care, met with organisations including the Alzheimer's Association Japan, the Ministry of Health for Japan and three local health ministry departments in Uji, Sendai and Setagaya, Dementia Care and Research Centre, Dementia Friendly Community Network Japan, Tokyo Metropolitan Institute of Medical Science, Shinko-Fukushima-Kai Social Welfare Corporation and NHK (Japan’s equivalent of the BBC).
4.1.2 USA

During my time in the USA I met with key individuals and organisations to hear about the work of the Administration for Ageing, National Alliance for Caregiving, Patient Centred Outcome Research Institute, LEAD Coalition, Cognitive Solutions, Alzheimer Association and the work of US Against Alzheimer’s. I spent a week with Kaiser Permanente in California and learned about their improvement work and their focus on dementia and person centred care.

4.2 Comparing Dementia Strategies

4.2.1 Japan

Whilst in Tokyo I was privileged to spend time with the Ministry of Health for Japan who shared their Orange Plan (Japan’s dementia strategy). I heard about their human rights approach and of the change in terminology to reduce stigma (see figure 1). Like Scotland, Japan has a working group of people with dementia, and their voices have a key contribution to the strategy. Both countries have the same over-arching themes – to support people with dementia to stay well at home for as long as possible and remain connected to their communities. The Orange Plan has seen the establishment of an Initial Phase Intensive Support Team within the Community General Support Centre and the introduction of a dementia co-ordinator role in local governments. The co-ordinator conducts home visits and assessments and provides information and advice. This role is similar to that of the link worker role in Scotland.

Scotland is the first country world-wide to have a Government guarantee that anyone diagnosed with dementia has a minimum of one year’s post diagnostic support with an identified link worker. The link worker uses the Alzheimer Scotland 5 Pillars Model http://www.alzscot.org/campaigning/five_pillars as a framework for supporting this person to self-manage in the community for as long as possible. Once that person is unable to self-manage and requires more intensive support from health and social care, the Alzheimer Scotland 8 Pillars Model is then appropriate and is currently being tested within five health and social care partnerships in Scotland.

![Figure 1](image-url)

4.2.2 USA

In Washington DC, I had the opportunity to hear about the National Alzheimer’s Disease Plan (the USA’s equivalent of the UK’s dementia strategies). The Plan was signed off by President Obama in 2012 and is annually updated. At first glance it seems to focus on finding ways to prevent and effectively treat Alzheimer’s by 2015 as the main priority, and so I was heartened when I had discussions with key individuals and organisations that there is much more to the Plan. Enhancing care for people with Alzheimer’s disease, expanding support for people with dementia and their families, improving public awareness and
carefully tracking data to support these efforts are also part of the plan, and it is these areas which grabbed my attention during my visit. Unlike the UK there is no national health system and so I learn about the complexities of health insurance in the USA and how Medicare and Medicaid are supporting the health needs of people with dementia.

Through my discussions with Government officials, lead organisations and individuals leading dementia practice in Japan and the USA, I got a sense of the scale of the challenge, but also about the efforts to continue to drive care quality for people with dementia and their family carers. The case studies in this report aim to provide a flavour of dementia policy in practice and of the innovation I witnessed. They capture my feelings and experience in the moment and are based on the extensive notes which I took during my travels which informed my published blogs. The case studies have been set within the context of the 8 Pillars Model in Scotland, with a particular emphasis on the Personalised Support and Community Connection pillars.

4.3 8 Pillars Model in Scotland

Figure 2: Alzheimer Scotland 8 Pillars Model
The Alzheimer Scotland 8 Pillars Model (figure 2) provides a comprehensive, integrated and coordinated approach to supporting people with dementia, their families and carers. The model includes the introduction of a dementia practice co-ordinator function, which will ensure access to all pillars of support as appropriate to each individual. Other pillars include support for carers, personalised support, community connections, environment, mental health care and treatment, general health care and treatment and therapeutic interventions. An improvement collaborative has been established nationally to support the test sites to learn about improvement, progress, challenges and opportunities, and to share data.

This work takes a therapeutic approach to enhancing the resilience of people with dementia and their families and carers: equipping and supporting them to cope with the symptoms of the moderate to severe stages of the illness. The results of this work will inform the third National Dementia Strategy for Scotland in 2016 and will make recommendations about the adoption, spread and sustainability of this model in practice.

Whilst Japan and the USA are not using the 8 Pillars Approach per se, I saw innovative examples of practice which fit well with this model, in particular around the personalised support pillar and the community connections pillar. These two areas will be explored further within the case studies which follow.

4.4 Community Connections

The Community Connections Pillar of the 8 Pillars Model aims to support the person with dementia and their carer to maintain and develop social networks to benefit from peer support (Alzheimer Scotland).

Group homes in Japan presented an exciting opportunity for people to continue to live in a homely environment and stay connected to their community.

4.4.1 Case Study 1: Group Home Natsgino

One of the most moving days I have in Japan is visiting the Group Home Natsgino. I see where the earthquake and Tsunami of 11 March 2011 hit this town. There are now many green fields and rice fields, where houses once stood. I remember vividly the news reports from the tsunami but it is only by being here that I appreciate the magnitude of this tragic event.

Mr Yomogida and Mr Okuyama who run the group home tell me of the devastating impact of the tsunami. This group home, which at that time was two years old, was completely demolished. They tell me seven people from the group home died as they were unable to run to escape. The 11 remaining residents lived at the other branch of the group home until temporary accommodation could be built. This meant that 29 people were living in a group home designed for 18. Residents had to share rooms designed for individuals, in some cases four people in the same room. This situation impacted on people’s general health and their dementia symptoms. After six months, the temporary accommodation was ready and with the support of local volunteers and family members, everyone was moved on the same day. The situation had a negative impact as people’s daily living and environment was now different. Other people with dementia, whose family had been killed in the Tsunami, had also joined the group home. There was now a drive to re-connect people with the local community. Since moving into the new premises this connection with the community has been ever strengthened. A garden plot has been established and people from the group home, along with people from the community, grow and pick vegetables together. Since March 2014, staff from the group home and key people from the community meet every two months to share progress and the vision of the group home.
An ‘Orange cafe’ has been established. It was felt that a ‘dementia cafe’ was not the right term as this was about bringing people from the group home and the community together, regardless of whether they had dementia. People attending may in the future be affected by dementia and so having this connection and familiarity with the group home will equip them for the future. The local authority provides transport for people unable to get there on their own. This acts as a safety mechanism as, for example, if the person doesn’t answer the door they can check that the person is ok. This is beneficial as many elderly people are living on their own, particularly as a result of the tsunami, so this is a way to integrate them into the community again. Later in my tour of the group home I see the room where the Orange cafe is held on a monthly basis. This is a lovely bright room with light wooden flooring, dual aspect windows and a balcony looking over the green fields and vegetable plot. Attendees pay a nominal fee of 100 yen (50p) but there is no strict rule about payment, as this is just a small contribution to tea and cake, but importantly it creates a sense of responsibility for staff and the public who attend.

**Personalised Support and Therapeutic Interventions**

I see photographs demonstrating the types of individualised activities which the group home residents enjoy. Due to the size of the home (18 residents) the staff are very familiar with their previous occupations, where they have travelled, their likes, dislikes and of course their families. The first photograph is of a man cutting a fish. Mr Okuyama tells me that this man used to be a fisherman and so staff went to the fish market and brought back a fish for him to cut, clean and cook and they all enjoyed eating this together. Another photograph is of a few ladies at the florist shop and they are making a floral arrangement, while another photograph shows a lady cooking and another shows a man holding a ‘para chan’ (the robot seal). I have heard about this therapeutic intervention so it is great to finally meet the para chan and see it in action. All the activities and therapeutic interventions are tailored to what is important to the person. There is no schedule of pre-planned activities. Even the Orange cafe activities are planned by the attendees based on what they would like to do; the only thing that is set is the date so people know when to come and flyers are disseminated locally to advertise this.

**Meeting the residents**

As I walk through to the open plan dining area I am blown away by what I see and hear. Everyone is sitting around a large table with welcome banners and hand painted (by the residents) Scottish flags. They are singing Auld Lang Syne to me in Japanese and they have the most beautiful smiles. After composing myself I tell them that they have made my day. I am introduced to everyone and I talk to a 105 year old lady. She speaks excellent English as she used to live in New York. This lady has seen a lot in her lifetime – World War II, earthquakes and the tsunami and yet she holds my hand, looks deep into my eyes with a lovely smile and says “I am so happy”. My heart melts!
4.5 Dementia Friendly Communities

Dementia Friendly Communities and Dementia Supporters was first introduced in Japan in 2005 and Japan now has over five million dementia supporters. Dementia supporter GPs was recently introduced to encourage GPs to be more actively involved in supporting people with dementia, in particular reducing stigma and promoting timely diagnosis.

The concept of dementia friendly communities was adopted by the UK and has been given a higher profile as part of the Prime Minister’s challenge in England in 2012. Work has been supported by Alzheimer Scotland, working with local partners to reduce stigma and raise awareness of dementia, and has recently supported Motherwell town centre to be the first dementia friendly town centre in Scotland, attracting much attention both from within the UK and from other European countries. There is an on-going commitment from Alzheimer Scotland to support such developments and the organisation is also supporting the Dementia Friends Campaign in Scotland, based on the work taken forward by the Alzheimer Association (England) and the Dementia Supporter concept which originated in Japan: http://www.alzscot.org/dementia_friendly_communities

Figure 3: Dementia Friendly America vision
Dementia friendly communities has now been introduced in the USA, namely Dementia Friendly America initiative. The work is being taken forward in collaboration with over 35 lead national organisations in the USA working with local communities. Their recently launched website has many tools and resources to support communities in the USA to become dementia friendly. The initiative is receiving much public attention and gaining momentum. Figure 3 demonstrates the vision for Dementia Friendly America.

As part of this trip, I visited the dementia friendly town of Uji City in Japan, the first dementia friendly community in Japan.

### 4.5.1 Case Study 2: Uji City

In a declaration made by the Mayor in March 2015, the city is working towards ensuring that its residents enjoy the “longest healthy longevity in Japan” and developing “a dementia-friendly city.”

I am here today to meet the local health ministry, health and social care staff and people with dementia to hear more.

Uji city has a population of approximately 190,000 people, of which 48,000 people (approx 25%) are aged 65 or over. Their vision for a dementia friendly city includes the following: A city:

- which does not exclude people with dementia from the community
- which comes together as a community to support families providing care for people with dementia
- where people with dementia feel comfortable to talk about their condition
- where people with dementia can receive the medical treatment and care which are correctly suited to their respective symptoms while they are still at an early stage
- where people with dementia can participate in community activities
- where people with dementia can be themselves
- where people with dementia can live at ease

Dr Toshio Mori, a psychiatrist specialising in dementia, advises that overcoming obstacles that prevent people with dementia from arriving at medical treatment and care at an early stage is key to Uji City meeting its vision. He describes these obstacles as “entry problems” which can be as a result of a negative image of dementia, poverty, isolation, people with dementia refusing intervention, and complex family issues. He says that even when people with dementia arrive at a source of medical treatment or care, they can be excluded from receiving such treatment or care, for example due to the support frameworks being under developed or not yet available. Uji City is making great progress in tackling these entry problems and is receiving much attention internationally. As part of the dementia legacy event in Japan in 2014, G7 colleagues visited Uji City to hear about their vision and progress. I hear about some of the developments including approaches to identification of people who need support, specialist assessment tools, early stage intensive support visits, outreach support and of course the Lemon Cafe.

I am introduced to members of the dementia working group; people with dementia from a range of different professions and backgrounds but with the same ambition: to improve the lives of people with dementia and their families. One of the members represented Japan in the last Olympic Games in Tokyo, and others a classical guitarist, a professor and a general
manager. I am inspired as I hear from the members and their families about how they are being supported and supporting each other to live well with dementia.

I see a clip of them playing tennis together and I watch smiles around the room as everyone remembers these happy occasions. Most had never played tennis before but now they are bonded by friendship rather than a diagnosis of dementia. I hear about the Lemon Cafe and how this provides a place in the community for people with dementia and their families to come together. The lemon cafe is held in six locations throughout the city. Dr Mori tells me that the cafe provides a place where people who have concerns about dementia or family members can ‘casually’ seek advice without having to visit a medical or nursing facility. The cafe also acts as a forum for community residents and specialists to learn and develop a sound understanding of dementia by meeting and interacting with people with early-stage dementia. Dr Mori says “Together these objectives create a place in the community which brings together people with dementia, family caregivers, specialists, and community residents, which in turn develops into a visible care network.”

I watch a clip of the dementia working group and their families picking tea leaves on a day out with Dr Mori and colleagues. They are all having such fun and there is laughter and smiles around the room as we watch the clip. I then have a nice surprise as it is time for tea, but not just any tea, this is from the very leaves which were picked that day – the best tea I have had since arriving in Japan! As we drink our tea I ask people with dementia about the differences which are being made in Uji City. I feel moved as they reflect on their initial experiences of getting a diagnosis of dementia and coping with this diagnosis at a time when there were not the support mechanisms they have now. They tell me that the work they are doing now to support the changes in Uji City is not only benefiting them but also provides people with hope for the future. As we drink our tea together I am so grateful to have this experience of meeting such inspirational people who are testament that there is a positive life after a diagnosis of dementia.

Photograph of the Working Group of People with Dementia, their families and health and social care staff in Uji City, presenting a traditional Kyoto fan to Michelle Miller.

4.6 Contributing to the Community – employment opportunities

One of the most inspiring days during my Fellowship, was visiting the BLG Day Centre. This day centre is like no other I have witnessed. It is supported by Dementia Friendly Communities initiative in Japan and the Japanese Government and is supporting people with dementia to contribute to their local community, by developing employment opportunities.
4.6.1 Case Study 3: BLG Day Centre

As we drive to the Day Centre, one of my Japanese colleagues from Dementia Friendly Communities Japan advises that this is the most innovative day centre he has witnessed in Japan. I am therefore intrigued to see what makes it so special. On first impression, the centre is not like a traditional day centre. It has lots of art work on the walls and is bright and modern. As we sit around the table, I see innovation in action. One of the care home staff has a white board and she advises that there are some important jobs for today and she is looking for volunteers.

The jobs are:

- working at the Honda garage – there are 3 cars to be washed
- folding leaflets and delivering these in the local area
- cleaning the barbecue

She adds that “once the work is finished, we are looking for volunteers to go and buy the ice cream.”

After stressing the importance of each of the jobs, she soon has willing volunteers for all of the tasks and the men going to the Honda garage go off to get changed into their Honda uniforms, whilst the others get set for their tasks.

I speak to the day centre manager through my translator – he tells me that the people who attend the day care centre all have dementia and are keen to continue to work and make a contribution to their local community. Whilst they are no longer able to do their old job, the day centre provides a new opportunity for them. I admire his tenacity and entrepreneurial spirit as he tells me how he has engaged with the local community and large businesses to set up these working arrangements. He makes this sound easy but colleagues advise that this has required nearly two years of negotiation and convincing of win-win benefits, but now the arrangements are in place and all is working well with positive results.

It is predominantly physically well men in earlier stages of their dementia who attend this centre. There is one lady at the centre today. She gives me a warm welcome and tells me that she used to be an art teacher. I see her work up in the wall of the day centre – she has drawn portraits of all of the day centre members and staff. The care staff ask her if she would like to draw me. As I sit for her at the table I am amazed at her skill and how quickly she is able to capture me on paper.

I’m invited to the Honda garage next to see the men at work. I take the opportunity to speak to the Honda garage staff and they tell me of the benefits of this working arrangement. Some staff are now able to start work one hour later as they don’t need to wash the cars. They tell me that they are very happy with the arrangement and that the customers are too. For the men there is a real sense of making a valuable contribution and of satisfaction with the end product – three shiny new cars!

We head back to the day centre and some of the men are busy with the leaflet folding and the others have gone on their deliveries. A few others are heading off with one of the day centre staff to buy the ice cream.

As we sit together at the table eating our ice creams, my first green tea ice cream since arriving in Japan, everyone is animated and chatting. What happens next is amazing; the care worker reminds each person individually at the table what their contributions/the jobs
they did in the morning were and what they achieved. She asks them how they feel about the work they have done, she then reminds each individual what they had for lunch and asks how they enjoyed the lunch, and she then reminds people about their afternoon activities and asks how they feel about this. She then asks for any other comments on their day. All of this information is documented and recorded. The day centre manager advises me that this activity happens every day to round up the day. This activity is not only about gathering experience but also about acting as a prompt to help people remember their day. I am inspired! This simple round up of the day has such impact. It values the contribution that people make, it creates a sense of self worth and boosts self esteem and it brings people together to share their experiences of their day.

4.7 Personalised Support

The Personalised Support pillar of the 8 Pillar Model in Scotland is focussed on providing flexible and person centred services to promote participation and independence for people with dementia. I saw inspiring examples of this ‘pillar’ in action during my travels and heard about exciting developments.

In the USA I heard how Kaiser Permanente are collaborating with Gunderson healthcare system to learn from their Respecting Choices Programme work, and develop a new Life Care Planning Programme to support personalised planning, particularly for people with chronic conditions and people with advanced illness (including people with dementia). Kaiser Permanente are also collaborating with the Dutch health system to support people with a diagnosis of Parkinson’s disease and considering how the learning from this work can be tailored for people with dementia. During my visit to their offices in California, I heard about the value placed by Kaiser Permanente on patient experience and I was interested to hear about the new Care Experience Standards ‘Care About Me’ which are currently being developed to support high quality person centred care.

During my visit to the Institute for Healthcare Improvement (IHI) in Boston, I heard about the ‘Conversation Project’. This is a public engagement campaign advocating “kitchen table” conversations with family and friends about wishes for end of life care. The project aims to ensure that every person’s wishes for end-of-life care are expressed and respected. IHI state that, ‘the Conversation Project is not about promoting any specific preference for end-of-life care; instead, it seeks to encourage and support people in expressing their end-of-life wishes for care’. Resources including a website and starter kit are available. IHI are currently looking to see how these resources could be adapted for people with dementia and their families.

In Japan I visited day centres which were focused on ensuring the needs and preferences of individuals were taken into account when promoting participation and independence. Ketara Home and Professional Works Day Centre are great examples and captured in the case studies below.

4.7.1 Case Study 4: Ketara Home

Ketara Home is a group home and a day centre for people with dementia. As I walk into the day centre I see that this once private house still retains its homely style. This is an open plan house with two seating areas, a large dining table and a small kitchen. Mrs Tsuboi who runs the centre advises me that we will all be having lunch together. There is a hive of activity in the kitchen – two ladies are chopping vegetables and another lady is cleaning the salad. Before too long more ladies volunteer to help and they each have their own jobs with staff providing encouragement and support. At the dining table a lady is making potato salad and she welcomes me in English and tells me she worked at the city Government before she retired. Another lady is helping place fish into baking trays and another is cutting melon.
At the seating area a lady is reading out today’s menu to a group of ladies and when she finishes everyone claps. Today we are having Chinese soup, potato salad, salmon, broccoli, carrots and then melon. One lady is sitting with a book, some ladies are talking to staff, whilst a man and another lady sit chatting at a quiet area near the piano.

Mrs Tsuboi advises that there are 14 people with dementia and eight staff (including one nurse, two cooks and care staff). She tells me that 30% of people who attend are aged over 90. People are predominantly at the moderate stage of their dementia. There is one young person with dementia in her 50s. She likes shopping so her ‘job’ is to go to the local shops to buy the vegetables.

As Mrs Tsuboi introduces everyone individually to me I can tell this is a lady who is in the right job – her compassion shines through and she brings such joy to the faces of the people she interacts with. It is clear that she knows everyone very well but still gently prompts people to tell me something about themselves, like the job they used to do, their age and about their families.

I am introduced to a 96 year old lady. As we rely on a colleague translating for us, she suddenly starts speaking Italian and I am then able to have a conversation with her directly despite my very broken Italian. She tells me that her aunt was a painter in Italy and that on her return to Japan after 53 years had forgotten how to speak Japanese and so she had interacted with her in Italian. She tells me how much she likes to come to this facility and how nice the lunches are. Another lady has now voluntarily come to help with the lunch; she is helping staff with setting the table, another lady is counting the plates and another is placing the chopsticks on the table. The room is filled with smiles, chatting but also calmness amongst the busy lunch preparations.

As we all sit together and enjoy lunch we talk about the typhoon which is forecast for later this evening. They ask about Scotland and for once I am grateful for Scottish weather (no typhoons or earthquakes)! The food is nutritious and delicious. Thanks to the thoughtfulness of Mrs Tsuboi, I eat with a fork as an alternative to chopsticks, and drink English tea from a cup & saucer with a thistle on it, which she has specifically selected for me. Mrs Tsuboi tells me that this house was once her family home. It still retains such a homely atmosphere. The staff advise me that there is no rush to eat lunch, one lady takes a whole hour to eat lunch but eats everything with very gentle encouragement. She is smiling at the carer and others around the table.

As I leave the day centre and make my way to the Group Home, I think about the ladies making lunch and how happy they are being able to do things that they have difficulty doing in their own homes. There is no sophisticated list of activities, the focus is on enabling people with dementia to continue to do the daily activities they have always enjoyed.
4.7.2 Case Study 5: No Ordinary House

As we walk down the street in Suginami one of Tokyo's suburbs, all the houses in the street look the same. We stop outside one of the houses and my colleagues inform me that we have now arrived at the day care centre for people with dementia. There is a small sign at the door which is the only indication that this is no ordinary house! I have come here with colleagues from the Ministry of Health in Japan and Ms Yumi Shindo from the Dementia Care Research and Training Centre in Tokyo.

We receive a warm welcome at the door from Shimada, Kawai and Okumura (Director and staff from Professional Works Day Centre). We exchange our shoes for slippers and we go upstairs to a traditional Japanese style room with a low table and cushions on the floor. We exchange business cards and make introductions. The house was built 40 years ago and was once the family home of the day centre director. People of all ages and stages of dementia attend the Professional Works Day Centre. These are people from the local area and many of them have lived in the same style of house so the layout is familiar to them as are the people who have been their neighbours. People arrive for 10 am and leave at 5 pm. We see photographs of the people undertaking daily activities. The centre has its own transport so they are often out and about going shopping or for a picnic.

What is special about this day centre is that there is no pre-planned itinerary or list of activities; the people with dementia decide themselves how they would like to spend their day and the five members of staff are there to support their needs. People can have a bath and this can be at the time that suits the person rather than as part of a schedule.

We enter the main room of the house with an open plan kitchen, dinner table and seating areas. There is a quiet area which can be screened off if required should anyone need quiet space or privacy. We meet a lady aged 101 who is folding small towels which she is placing into a basket; the staff thank her for her help and she smiles. There is a real sense of people supporting and helping each other and of people feeling valued by contributing to meaningful activities. At a small table a man is listening to 60s music – this is music he has chosen himself and is enjoying this whilst drinking his tea which he pours from a traditional Japanese teapot. He smiles and makes a joke about having shaved if he had known I was coming. I advise him that beards are the height of UK fashion these days! We get our photo taken together. Another lady decides it's too nice a day to be inside and she and a member of staff go outside to chat in the sunshine. At the table, a few of the ladies decide they would like to make pancakes. The member of staff asks the ladies what they need for their pancakes and they go to the fridge and choose their ingredients together. The hot plate is set up on the table within easy reach of the ladies, and the ladies begin to put together their pancake mix. One lady decides to whisk her mixture with chopsticks. There is such joy on these ladies’ faces as they chat together. People of differing abilities support each other. Each person around the table has a contribution to make to the pancakes and they use
scissors and a knife without panic from care staff. One lady is struggling to reach the pancakes and despite being frail, she stands up and has great joy in flipping over the pancakes. The staff do not take over, they are there to support and to ask questions to prompt people to come up with their own solutions, promoting a sense of independence. The staff explain that these tasks have been done by people all of their lives, so they know what they are doing and now just need a bit of encouragement and support to continue to do the things they enjoy.

As we leave the day centre after saying our goodbyes I reflect with colleagues on how homely the environment is. It just feels like a group of neighbours meeting to catch up at one of their houses, but this is certainly no ordinary house and the compassion and patience shown by the staff is so palpable in supporting people to do what matters to them without any pre-planned schedule or checklist.

4.8 Supporting Diversity

There is much to learn from the USA in how it is supporting a very diverse culture. During my time in the USA, I heard from the Alzheimer’s Association about their innovative programmes and initiatives. I heard how the Association is raising awareness of dementia amongst diverse groups and about the ‘Open House’ programme to support the LGBT community. During my visit, I had the opportunity to go to the Diablo Centre, an Adult Day Healthcare Centre where people with mid to late stage dementia are being supported to live well.

Michelle Miller with Debbie Toth (Manager at Diablo Centre) and Ruth Gay (Alzheimer’s Association California), Diablo Centre

4.8.1 Case Study 6: Diablo Centre

This centre prides itself in personalised care planning and individualised multidisciplinary support. Whilst activities are delivered in a group setting, much careful planning is undertaken prior to and during the session to ensure appropriateness of activities and tailoring to individual needs and preferences. This includes the social worker visiting the person’s home to understand their requirements, and a tailored plan developed by the nurse, occupational therapist, physiotherapist and social worker, with input from a physician and speech and language therapist where required. Whilst at the centre I observe the compassion shown by staff, the tailored communication styles and the calm and happy environment created. I watch the smiles on the people’s faces as they take part in activities with the co-ordinator.

Responding to diverse needs is further emphasised as I pass through two other areas of the centre. These areas are not specifically for people with dementia. In one area is a support group for women who have emigrated from Afghanistan. Many of the women have post traumatic stress and I see the private prayer area created for them, the beautiful hand crafts they have made to send back to Afghanistan and then I meet the ladies in person. They are sitting in the shade of the Californian sun and are chatting and laughing together in their native language. They say hello and they smile when I tell them I have come from Scotland.
and how much I prefer the Californian weather to our rainy climate. As I pass further through the day centre I meet a group of people from Russia who are taking an exercise class and in the next room a group of elderly people who are also enjoying exercise to music with the physiotherapist.

In addition to community connections and personalised support, the case studies reveal three other strong themes:

- Culture (valuing ageing, intergenerational work and personalisation).
- Leadership (including a Social Movement for Change).
- Human Rights: (Supporting individualism, diversity and managing risk).

4.9 Culture

Japan could be described as having a conventional culture, predominantly Japanese people living in Japan and retaining many Japanese traditions including eating Japanese food, using chopsticks and many wearing traditional dress. I was struck by the compliance with rules and the efficiency of systems and processes - simple things like not crossing the road until the green man appears, standing patiently in line at the train station despite the rush hour and the train is always on time! A very stark difference to the often chaotic streets and train stations that I am familiar with in my daily western life.

However, there are signs of western influence, particularly in the large cities like Tokyo where young people have moved to the city for work to gain more independence and are no longer conforming to the traditional family culture of the rural communities.

Respect for ageing is a prominent feature. During my time in Japan I witnessed great examples of intergenerational programmes, for example, the day centre in Sendai where young children and people of all ages with dementia come together each day, reading together and sharing stories from the past. I remember vividly the smiles on everyone’s faces as all generations enjoyed each other’s company.

Within the facilities that I visited there is such flexibility in meeting the needs of the person with dementia. For me there seems to be a clash of cultures. Such flexibility against a backdrop of conformity to rules. Is it just that the respect of people and individualism overrides the rules or is dementia care attracting a particular personality type, willing to forego rules in respect of individual wishes?

I reflect on the amazing sites I visited including the beautiful Kinkakuji (Golden Pavilion) in Kyoto. I hear how this temple is quite unique. Many temples in Japan which were once golden or brightly decorated are now old and brown in colour. Unlike other countries in Asia, for example China and Thailand, Japan does not restore temples back to their former glory, but instead the age and different stages of the temple are respected. Could this valuing of age be a clue to how communities in Japan respect their older people? Surely valuing every stage of life is something we should all strive towards? I contrast this with our western culture, our marketing campaigns for the latest cosmetics and styles all in an attempt to defy ageing.
4.10 Leadership and a Social Movement for Change

There is no doubt that where dementia care is good it is by design and not by accident. Leadership qualities including tenacity, resilience and passion are visible in the inspiring leaders I have met during my travels. These were people at all stages in their lives and careers.

During my time at the Institute for Healthcare Improvement in Boston and Kaiser Permanente in California I had the privilege of meeting improvement leaders from across the USA. I heard about the exciting improvement initiatives they are leading. Their priorities for improvement, like Scotland, include dementia and person centred care. I had the opportunity to spend time on the Professional Improvement Leaders Programme. This is an exciting development programme led by Kaiser Permanente to build leadership capability and capacity amongst its quality improvement leaders and they are an inspiring group. I had the opportunity to share the work of Focus on Dementia, to experience visiting dementia services in Japan and the USA and to reflect together and learn from their insights and experience.

Leadership is at all levels and one of the most inspiring days of my Fellowship was spent at a Group Home in Sendai which had been devastated by the 2011 tsunami. The members of the Group Home were the most amazing resilient people who were not only supporting each other through their losses caused by the Tsunami but were also supporting the local community to avoid social isolation. Through their ‘Orange Cafe’ they brought together people from the community, regardless of whether they had dementia or memory worries. This was about peer support, building resilience and re-building a community which had been devastated by loss.

The day centre leader at the BLG day centre is another great example of a tenacious leader with a passion for making a difference. It took two years to convince the Honda garage management of the win-win benefits of people with dementia working at the garage. Today it is a great success – people with dementia are again making a meaningful contribution to their local community and some of the Honda garage staff can now start work later in the morning as they have fewer chores. This was achieved through the perseverance and vision shown by the Day Centre leader and his determination to make improvements which were key to success.
For me some of the strongest leaders who are contributing to a social movement in dementia care are the people with lived experience.

Throughout my travels I met people who are campaigning and speaking out to reduce stigma and improve the experience. They are supported by the voluntary sector (Alzheimer’s Society and in Scotland Alzheimer Scotland), and their voices are being heard by policymakers, practitioners and communities.

During my time in the USA, I learned about public health campaigns such as ‘Know the Ten Signs’ and ‘Healthier Habits for a Healthier You’. I heard about annual advocacy events where 1,000 people with an interest in dementia (many with lived experience) come together with Congress to share experiences and keep the spotlight on dementia at the most strategic level. I have heard that the Alzheimer’s Association have 600,000 advocates for dementia. I have learned about the Center for Medicare and the Medicaid Innovation Fund and how these projects are informing practice. I learned about patient powered research networks and how they are supporting and valuing the experience of people living with dementia as part of the research agenda. I have heard how 77 organisations are collaborating on dementia through the LEAD Coalition to share practice, ideas and work together as a force for change.

In Japan, I heard how they have learned from the Scottish Dementia Working Group and have now established their own equivalent. On the day I spent with a group of people with dementia and their carers, together with a Neurologist, local Government staff and the Mayor of Uji City, it was clear that these people were not bonded by a diagnosis of dementia but by the strong friendship and relationships they had developed.

In Scotland we are fortunate to have the Scottish Dementia Working Group, National Dementia Care Action Network and Dementia Carer Voices. Key to the success of the Dementia Strategy in Scotland has been undoubtedly the partnership working with people with lived experience and third sector colleagues, in particular Alzheimer Scotland, and the continued commitment to a Human Rights approach.

4.11 Human Rights: Valuing individualism, diversity and risk

I consider the limitations we put on people in the western world for perceived fear of health and safety and increasing litigation culture. I have seen how compliant cultures such as Japan are, and yet they have ‘permission’ to support people to take the ‘risks’ that will make their lives meaningful. The hot plate on the middle of the table as the ladies laugh while they flip pancakes will stay with me forever. As I shared this image and experience with staff back in Scotland during a Spotlight Session with Alzheimer Scotland, there were smiles and gasps in the room. This triggered some useful discussions about what was perceived as our risk averse culture and whether we are in danger of internalising risk and assuming barriers will be in place before exploring all options.
I am reminded of Atul Gawande’s book ‘Being Mortal’. In the book Gawande challenges Maslow’s Hierarchy of needs. As a core text of my MBA studies I am intrigued by his views and consider them in the context of dementia care. Maslow’s theory is based on the assumption that physiological survival (food, water, air and safety) is everyone’s priority. However, Gawande argues that the reality is more complex. People demonstrate a willingness to sacrifice safety and survival for something beyond themselves, such as family, regardless of age. Is it our parental approach to people with dementia that makes us consider safety to be paramount in our western society and is the reality often quite different? We ourselves are willing to take risks for the people and the activities which mean most to us – going out in snowy or stormy weather, cycling or hill walking. Does this have to change just because we have a condition called dementia? For many families safety will be the most important factor for their loved one but for that person the opportunity to do the thing they most want in the world may be their deciding factor. For me, there is a balance to be struck. Yes – we want people to be safe but at what expense – denying people their human rights?

4.12 Creating the Conditions for High Quality Dementia Care and Support

From the findings and case studies described in this section, it is clear that I witnessed innovative examples of practice and I have much to share and learn with Scotland and the rest of the UK. However, Scotland and the remainder of the UK should not shy away from their achievements over the last 10 years to improve dementia care. We have much to be proud of with dementia strategies which focus on the quality of care for people with dementia which have been developed in partnership with people with dementia and their families. Scotland has one of the highest diagnosis rates of people with dementia in the world and some of this may be due to the commitment Scottish Government has made around the post diagnostic target for people with dementia and through raising awareness and reducing stigma of dementia. However, there is no room for complacency and much to learn from other countries. What does strike me is that, regardless of the country (Japan, USA or UK), there are 3 fundamental elements to creating the conditions for high quality care and support for people with dementia. For me these are:

- Culture (valuing ageing, intergenerational work and personalisation).
- Leadership (including a Social Movement for Change and reducing stigma), and
- Human Rights: (Supporting individualism, diversity and managing risk).

I would agree that if we can get these 3 areas right then high quality care and support will follow.
5. Returning Home: Making an Impact

5.1 Dissemination of Findings

5.1.1 National Impact

Since returning home, I have had the opportunity to share and reflect on my experience with colleagues, friends and family. We have discussed the different cultures and traditions and how this may be influencing the support for people with dementia in the community.

Through presentations and webinars to colleagues at Scottish Government I have had the opportunity to generate discussion and discuss similarities and differences within the Scottish context.

I met with the Chief Executives of Alzheimer Scotland and Playlist for Life to share my findings and ran sessions at Alzheimer Scotland resource centres to share my learning and inform practice.

Michelle Miller at Alzheimer Scotland Shetland session sharing Winston Churchill Findings with people with dementia, staff, and carers (Feb 2016)

5.1.2 Spotlight Session: Learning from Asia

On 30\textsuperscript{th} November 2015, I led a session with colleagues from Alzheimer Scotland to share my findings with a wider audience of 60 Alzheimer Scotland staff, volunteers and health and social care staff working across Scotland with people with dementia and carers. Colleagues at Alzheimer Scotland also shared their experiences of China and Singapore which enabled wider discussion and comparisons.

Session aims were to:

- hear about the international context for dementia
- have a closer look at dementia innovation in Japan, China & Singapore
- have the opportunity to discuss similarities & differences between these countries and our 5 & 8 Pillar Models in Scotland
- identify opportunities to apply the learning in Scotland

The event was recorded and will be published on a podcast as a training resource. A summary report has been developed to share findings more widely and published on Focus on Dementia website:  
http://www.qihub.scot.nhs.uk/media/920776/dementia%20spotlight%20report.pdf  
The session was also captured by a graphic illustrator. See graphic below (figure 4).
5.1.3 Local Impact: Establishing a Dementia Friendly Community in my locality

Since returning home I have been struck by the different lens through which I see the town where I live. Prestwick is a small seaside town with a population of 14,391 (2001 census). Given the incidence of dementia, there could at any one time be 1 in 55 people with dementia in this town.

My travels have given me a heightened awareness of some great examples of how local people and businesses are supporting people with dementia. Through discussions with local residents and business leaders there has been a real willingness from people to enhance their knowledge and understanding of the condition in order to support people more. I have had the opportunity to share my findings through discussions with local community groups including locality planning meetings, the Charette (a town planning initiative) and with the Rotary Club who are already engaged in much charity work and keen to explore opportunities to work together. Prestwick, already a dynamic and forward thinking town with a strong community, presents an exciting opportunity for taking a dementia friendly initiative forward.

In order to drive this forward, I have established a Steering Group comprising key stakeholders in the community. In addition to myself, the group includes:

- people with dementia
- family carers
- Chief Executive of the Alliance
- Policy and Engagement Manager at Alzheimer Scotland
- Executive Nurse Director, NHS Ayrshire and Arran
- Partnership Facilitator, South Ayrshire Health and Social Care Partnership
- Community Engagement Officer, South Ayrshire Health and Social Care Partnership
- Councillor, South Ayrshire
- Prestwick Business Association representative
- Regional Manager, The Food Train
- Improving Care for Older People Programme Lead
- Buzzworks Business Group representative
This work is predicated on a bottom-up approach – a social movement – facilitated by key individuals including people with lived experience of dementia and their carers in partnership with local stakeholders who can influence local practice and provide support. This work has the potential to create a ‘blue print’ which could then be shared with other towns throughout the UK. As part of this work we will be connecting with other parts of the UK who are undertaking similar initiatives in order to share practice and learning.

Our facebook page and twitter account has now been established and is generating much interest and positive feedback. The local councillor for the area published an article in the Prestwick Going Out newspaper in February 2016 to share the initiative and my Winston Churchill findings.

Figure 5: Extract from Councillor Hugh Hunter’s publication in Prestwick Going Out local newspaper sharing Dementia Prestwick initiative

Figure 6: Dementia Friendly Prestwick Facebook and Twitter sites

Photo of Michelle Miller with Prestwick Rotary Club – where she presenting Winston Churchill fellowship findings and Dementia Friendly Prestwick initiative (Feb 2016)
6. Recommendations and Next Steps

My Fellowship experience has provided valuable insights into the quality of care co-ordination in the community for people with dementia in Japan and the USA and has enabled me to compare this with how Scotland is supporting people with dementia. I undoubtedly witnessed innovative examples of person centred care and how people with dementia are being supporting to remain part of their communities.

Dementia Friendly Communities and Dementia Friends was pioneered in Japan and the UK and USA are now following its lead. Scotland can learn from the innovative housing examples witnessed including group homes and day centres and Japan, and how the USA is supporting a diverse population of people living with dementia. However, this experience has also demonstrated that Scotland and other parts of the UK have much to share with other countries too. Our partnership approach to dementia policy development and implementation, with people with dementia and carers is helping to give people with dementia a voice in the UK. Japan has followed Scotland’s lead in this regard by visiting our Scottish Dementia Working Group at Alzheimer Scotland to learn more about this approach. The Scottish Government target on post diagnostic support is world leading and the role of link workers in supporting people with dementia in the community, together with our high diagnosis rates was of great interest to Japanese and USA colleagues during my travels.

What was clear from my Fellowship that regardless of the country (Japan, USA or UK), I believe there are 3 fundamental elements which create the conditions for high quality care and support for people with dementia. For me these are:

- **Culture**: (valuing ageing, intergenerational work and personalisation).
- **Leadership**: (including a Social Movement for Change and reducing stigma), and
- **Human Rights**: (Supporting individualism, diversity and managing risk).

These 3 areas provide the basis of the recommendations from my Fellowship findings.

6.1 Recommendations

- **Culture: Value ageing, support intergenerational work and personalisation**
  As a society we must strive to value ageing and the contribution that people with dementia can continue to make to our society. There are already innovative intergenerational projects where people with dementia and young people are involved in activities which keep traditions alive and promote shared learning and experiences. We should continue to build on these and share examples of good practice in this area in order to reduce the stigma of dementia and promote inclusive communities. This should be a key feature of dementia friendly communities.

- **Leadership: Support a Social Movement for Change**
  It is clear that the examples of innovative practice I witnessed during my fellowship were by design and not by accident. At the heart of these examples were tenacious leaders who were passionate about changing practice for people with dementia. We should continue to value these leaders in our systems, give them the right support, education and empowerment to drive improvements. Advocates for dementia care are all around us, in our communities and organisations. We must continue to give people with dementia and carers a voice in supporting improvements in dementia care and reducing stigma. For example through national and international events and through developing dementia friendly and inclusive communities.

A gap for me is in how we are supporting people with dementia to continue in employment. I saw a great example of supporting people following diagnosis of dementia to work again
through the BLG Day Centre in Japan, a model which could be replicated in the UK and in other countries across the world. However, I still think we have a way to go in supporting people within employment to continue within their existing employment, albeit within a different or modified role. I believe that dementia friendly communities could be an important vehicle in this regard and as such we should not miss an opportunity through this work to engage with employers to support people with dementia and carers to remain within employment for as long as possible.

**Human Rights: Support individualism, diversity and manage risk**

We are fortunate in Scotland that our dementia strategy is underpinned by a Human Rights Based approach. As we support the implementation of the strategy in practice, we must not lose sight of this ethos and of the Charter of Rights for People with Dementia. We must support individuals with dementia to achieve the goals and aspirations which are important to them as far as is possible. Within this context we must balance risk and value that different people will have different levels of risk. We should challenge the systems and processes that get in the way of supporting individualism and enabling people with dementia to continue to live well and fulfilled in their lives. People with dementia should not fit into our services and community assets, we should be co-producing these alongside people with dementia.

No single country has all the answers, and as such we should continue to build collaborations between G7 counties and beyond in order to share the best of our work and the challenges and opportunities we face. This could be achieved through sharing practice via webinars, international events, conferences and email exchange. As Winston Churchill Fellows, we should continue to share our learning in this area and build our network of contacts interested in improving dementia care and experience.

### 6.2 Next Steps

The next steps which follow have been developed as a direct result of my Fellowship experience and recommendations as set out in this report. Whilst ambitious, I believe these are all achievable and will make a valuable contribution to improvements for people with dementia and their carers in the UK.

<table>
<thead>
<tr>
<th>Development</th>
<th>Action</th>
<th>Progress</th>
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</thead>
<tbody>
<tr>
<td><strong>LOCAL DEVELOPMENT</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>➢ Develop Dementia Friendly and Inclusive Community for Prestwick</td>
<td>Develop Prestwick as a dementia friendly and inclusive community in order to reduce stigma, and enhance education and support to enable people with dementia to remain connected to their communities for as long as possible</td>
<td>Steering Group meetings underway (first meeting 29 February 2016) Action plan and engagement strategy being developed</td>
</tr>
<tr>
<td></td>
<td>Learn from other dementia friendly initiatives in the UK and beyond to identify opportunities to share practice across the UK</td>
<td>Local presentations to key groups and stakeholders to support social movement in dementia support in the community and reduce stigma. Meetings held with Prestwick Business Association and Locality Planning Group Jan and Feb 2016</td>
</tr>
</tbody>
</table>
Reviewing evaluation reports from other dementia friendly community work in order to learn lessons learned from across the UK.

### NATIONAL DEVELOPMENT: Informing policy and practice

- Inform Dementia Strategy for Scotland and support implementation into practice
  
  Inform the testing of the 8 Pillar Model of care co-ordination in the community in order to inform the next Dementia Strategy for Scotland
  
  Presentations to Scottish Government and Alzheimer Scotland Colleagues to share learning and inform policy and practice. Share reflections at Dementia Strategy Dialogue Events.

### INTERNATIONAL DEVELOPMENT

- Inform international dementia key stakeholders
  
  Continue to link with key contacts in USA and Japan to continue to share our learning, experiences and latest research and developments. Link contacts between other key stakeholders in the UK and EU to inform practice
  
  Sharing findings with colleagues involved in EU Joint Action on Dementia and G7
  
  Sharing findings with colleagues through international collaboration and events
  
  Presenting at BMJ conference in Gothenburg and Dementia Congress in the UK in April 2016 on personalised support element of this work
7. Conclusions

At the end of my Winston Churchill experience, I took a trip to Hawaii. Standing on the Battle Ship Missouri in Pearl Harbour, on the very spot where the surrender of Japan to Allied Forces took place on 2nd September 1945 (marking the end of World War II), provided a powerful final reflection point.

During my travels I have seen constant reminders of the links between the UK, Japan and the USA. I have seen plaques and memorials, museums and memorabilia reminding me of the devastation of World War II – and in particular of Pearl Harbour and Hiroshima. Visiting these two sites months apart brought home to me the loss and devastation of innocent lives.

I have seen evidence of the building of relationships between these countries, like the plaque in Monterey celebrating the 20 year anniversary of the twinning of townships Monterey and Nanao. I have seen people of all nationalities visiting museums and World War II sites to pay their respects, like the USS Midway naval museum in San Diego.

Last year (2015) was a symbolic year – the 50th anniversary of the death of Winston Churchill and 70 years since the end of World War II. As I stood at Pearl Harbour I considered how these countries are now fighting on a united front – the battle this time is not over territory and power but against one of the most feared and devastating diseases of our time – dementia.

Through the G7 collaboration Japan, the USA and the UK are working together with other countries across the world to find innovative solutions for improving the quality of care for people with dementia, to invest in research and ultimately to find a cure.

However, we know that many people with dementia can live well and, given the right support and care, can remain resilient and stay connected to their communities. It is this aspect of care quality which has been the focus of my Winston Churchill Fellowship and has taken me to Japan and the USA to compare practice with the UK in order to share insights.

During this time I have heard about the national plans and strategies for dementia and have seen how these plans are being implemented in practice. I have met key organisations and individuals at the cutting edge of improving dementia care and have been privileged to meet people living with dementia and their families and heard first hand what keeps them resilient and positive. I have been amazed by innovative examples of practice and of the vision of leaders at all levels with a passion for improving the experience and care for people with dementia and their family carers.

I have heard about the challenges of complex systems and healthcare insurance, of different cultures and of how diversity is being valued and supported. I have heard about social movements and how the voices of people with dementia and carers are being heard and valued. I have seen personalised planning and person centred care in practice and most of all I have witnessed compassion, dignity and respect – for me the heart of improving dementia care and support.

No single country has all the answers, but what is clear from my Fellowship experience is that regardless of the country (Japan, USA or UK), I believe there are 3 fundamental ingredients which create the conditions for high quality care and support for people with dementia. For me these are:

- Culture (valuing ageing, intergenerational work and personalisation).
- Leadership (including a Social Movement for Change and reducing stigma), and
- Human Rights: (Supporting individualism, diversity and managing risk).
Since returning home, I have been inspired by the support of people in my local community to work with me to take forward Prestwick as a Dementia Friendly Community. This bottom-up approach to driving a social movement around dementia is really exciting, with key individuals in the community supporting me to drive this forward. This approach respects the human rights of people with dementia and their carers by enabling and supporting people to continue to be a part of their community.

It is not only at a local level that I can influence support and care for people with dementia. As National Lead for Focus on Dementia at the Scottish Government I have had the opportunity to share my findings both nationally and internationally, to help inform the dementia strategy for Scotland through contributing my experience at table top discussions at dialogue events, and to share my experiences more widely with other UK and international colleagues.

At an international level we must seize the opportunity to continue to build collaborations between G7 counties and beyond in order to share the best of our work and the challenges we face. As Winston Churchill Fellows, we have an opportunity to continue to share our learning in this area and build our network of contacts interested in improving dementia care and experience and I look forward to playing a key role in this with my colleagues.

I am honoured to have had this amazing opportunity. It has exceeded all of my expectations and absolutely inspired me to make a difference to the lives of people with dementia and their carers.

The successes to date are not final and through continuous effort I am committed to supporting developments at a local, national and international level to enable people with dementia to remain a part of their local communities.

“Every day you may make progress. Every step may be fruitful. Yet there will stretch out before you an ever-lengthening, ever-ascending, ever-improving path. You know you will never get to the end of the journey. But this, is far from discouraging, only adds to the joy and glory of the climb”

— Winston S Churchill

I will remain eternally grateful to the Winston Churchill Memorial Trust for the experience of a life time.

Photographs taken at Pearl Harbour, Hawaii

“Success is not final, failure is not fatal, it is the courage to continue that counts”

— Winston S. Churchill
Appendix 1: References

1. Alzheimer's Association USA http://www.alz.org/about_us_about_us_.asp
3. Alzheimer's Association Japan http://www.alzheimer.or.jp/?page_id=2978
5. Alzheimer Scotland 5 Pillar Model and 8 Pillar Model http://www.alzscot.org/
8. Dementia Friendly America http://www.dfamerica.org/
Appendix 2: Itinerary

**Japan: May 2015**

Ministry of Health, Labour and Welfare, Chiyoda-Kun
Outpatient Long-Term Care for People with Dementia, Suginami-ku
Group Home Setagaya-Ku
Office of the local authority Setagaya-Ku
Tokyo Metropolitan Institute of Medical Science
OFUKU evening meeting of leaders in dementia care in Japan
Sendai Dementia Care Research and Training Centre
Sendai visit to social care service provider for elderly and children
Group Home Natsugi-no
Promotion of prevention of long-term care department at Sendai City Hall
Dementia Friendly Communities Japan – Business Community
Alzheimer's Association Japan (National Office), Kyoto
Uji City

**USA: October – November 2015**

Institute for Healthcare Improvement, Boston
Administration for Community Living/Administration on Ageing, Washington
Patient Centred Outcome Research Institute, Washington
US Against Alzheimer’s Programme/ US Congressional Task Force for Long Term Care Support Services, Washington
National Alliance for Care Giving
LEAD Coalition, Washington
Alzheimer's Association USA National Office, Washington
US Against Alzheimer’s, Washington
Walnut Creek Medical Centre (Kaiser Pemanente)
Kaiser Permanente, California (one week itinerary including dementia programme and quality improvement leadership programme)
Diablo Centre, California
Alzheimer's Association, California
Appendix 3: Reflection points

Japan: May 2015

- Hiroshima peace memorial park and museum
- Kinkakuji, the beautiful Golden Pavilion in Kyoto
- Miyajima Island with the beautiful temple ‘floating’ in the water
- Cycling along the river banks and narrow streets of Kyoto
- Cycling around the lush green countryside of Kyoto and taking in the nature and beauty of Japan
- Discovering ancient temples nestled in the trees and hills
- Sitting on the Bullet train from Tokyo to Kyoto and admiring Mount Fuji
- Sendai – the site of the tsunami and earthquake of 2011
- Uji City – first dementia friendly city in Japan

- Standing at the spot where Marin Luther King gave his ‘I have a dream’ speech in 1963 which would change American history for ever, and looking out to the reflection pool at the Lincoln memorial reflecting on Lincoln’s aspirations of equality
- Sitting at Conorado Beach, San Diego watching the crashing waves and pure white sandy deserted beach
- Cycling across the iconic Golden Gate Bridge and along beach fronts in Monterey, Santa Barbara and Santa Monica, taking in the drama of the rugged Californian coastline, white sandy beaches, wildlife and surf
- World War II memorials and reflecting on the history and loss of innocent lives
- Pearl Harbour, Hawaii

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