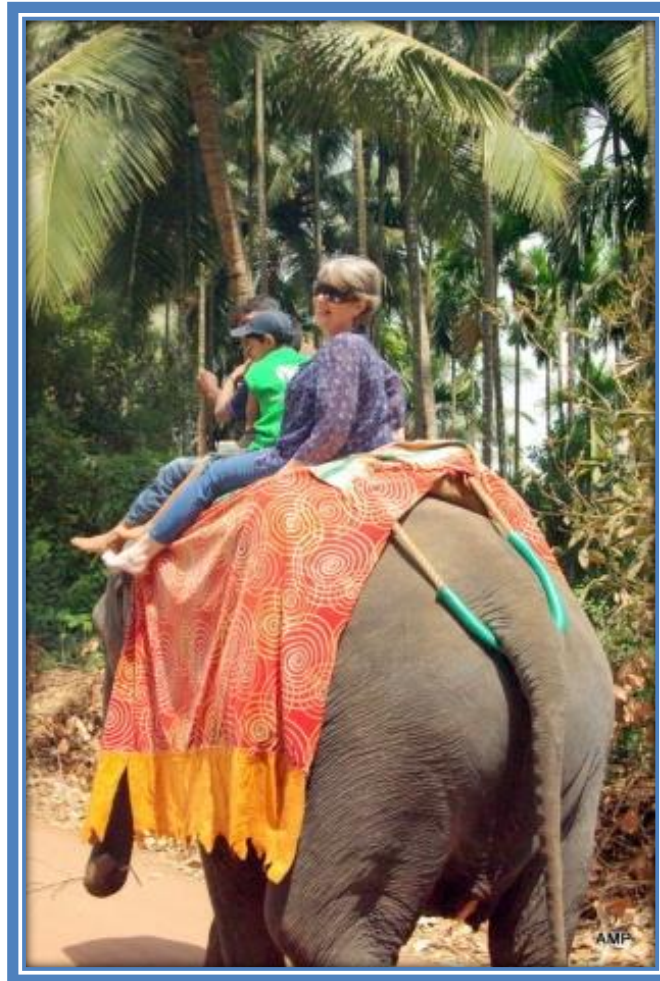


# Ann Pascoe



## **VISIT TO INDIA TO LEARN ABOUT EARLY DEMENTIA AND CAREGIVER STRESS AND WHAT CAN BE DONE ABOUT IT**

WINSTON  
CHURCHILL  
MEMORIAL  
TRUST



Made possible by a Winston Churchill Travel Fellowship

<b>Contents</b>	<b>Page</b>
<b>1. Executive Summary</b>	<b>3</b>
<b>2. Who are we?</b>	<b>5</b>
<b>3. Where did we travel?</b>	<b>7</b>
<b>4. Places/people visited in India</b>	<b>9</b>
<b>5. Back to the Scottish Highlands</b>	<b>32</b>
<b>6. Taipei</b>	<b>41</b>
<b>7. Vision for the Future</b>	<b>46</b>
<b>8. Substantiating Documents</b>	<b>49</b>

## Executive Summary

My name is Ann Pascoe and I live with my husband Andrew in Portgower, a rural hamlet in the Eastern Highlands of Scotland, so far north that in the middle of the winter we barely see the sun four or five hours a day.

But it was only when Andrew was diagnosed with vascular dementia seven years ago that I realised just how isolated we were. As a carer, I didn't know where to turn and felt totally cut off, but perhaps the real isolation came from being plunged into a world with little understanding about the reality of living with someone with dementia.

### **What prompted applying for my Fellowship?**

Those first steps into the dementia world were so isolated, so painful and so lonely that in 2010 I said "*enough*" and decided to do something about changing this. Applying for my Fellowship was the "*something*" that was the start of a remarkable journey.

One of the key issues facing us as a dementia family was that immediately anyone heard Andrew had 'dementia', the fear factor kicked in along with key issues around lack of information and knowledge about the illness, support for the family and carer stress. We learnt firsthand how this fear resulted in the betrayal of respect and dignity and that this was the reason why the stigma was so profound and indeed why Andrew refused to accept his diagnosis for the first six years.

I began speaking out about these issues and, in March 2011, heard Dr Amit Dias speak at the Alzheimer's Disease International Conference in Toronto. Blown away by what I heard, I applied for a Churchill travel grant to visit him in India to research his work on grass roots lay programmes to detect early symptoms of dementia and carer stress, but more importantly how to red flag these and do something about it. I was also invited to join the COPE intervention that the Sangath Organisation in Goa are developing with WHO, to work on qualitative research as well as the development of the training materials for Community Home Workers. And I took Andrew along with me...

One year on from India, Andrew has accepted his diagnosis and we are no longer alone, but rather supported by a socially inclusive community, indeed a dementia friendly community. And it was my Churchill Fellowship that gave me the wherewithal, but more importantly the credibility and networking, to link talents and resources to make change.

This report will capture how it happened.

## **Making a lasting difference?**

There is no question that the approach taken has raised the awareness beyond our wildest dreams. Local people are more aware, informed and involved. And Andrew now feels free to be part of any community activity, something he was not able to do before.

But, more importantly, by giving people with dementia and their families the wherewithal to retain a sense of well-being and remain fulfilled in their own homes, less pressure is put on social and health services and makes for happier people all round. Indeed, after six years of denial, Andrew has finally accepted his diagnosis resulting in a transformation in our own dementia world: we are no longer alone and simply get on with living their lives, but now within a community that is totally supportive.

Andrew teaches photography to kids with learning disabilities; he has joined the Highland Dementia Working Group, a division of the Scottish Dementia Working Group, an autonomous body of people with dementia who speak out for themselves. He also runs a carpet bowling group in Helmsdale and recently represented the Highlands at the Disabled Bowling Games in Edinburgh. Most impressively he has become extraordinarily creative and makes and paints clay animals and birds from his photography, something he has never attempted before.

But best of all, the concept of a dementia friendly community has caught on and the Enterprise has been able to galvanise a wide range of support, resulting in a growing interest from other areas in Highland. Together with NHS Highland and Alzheimer Scotland, local politicians and others, I am working to map the different strands of dementia friendly community work across the Highlands, so that a base line can be established for future work.

The culmination of my Churchill Fellowship was a trip to Taipei in April this year to deliver three papers at the Alzheimer's Disease International conference: the first, a paper on my dementia friendly community work; the second, on the power of the website; and the third a poster on my work with Amit Dias in India, who was at the Conference with me. Full circle and all as a result of my Churchill Fellowship!

On my return from Taipei, I was appointed a Trustee on the new BIG Lottery £50 million Life Changes Trust, set up to be a game changer. There is no cure for dementia and since the only available treatment is human therapeutic intervention, the Trust aims to deliver cutting edge support in dementia by using innovative and out of the box thinking. So watch this space ...

### **Ann Pascoe**

Portgower, Scotland

22<sup>nd</sup> July, 2013

Email: [ann@dementia-friendly.com](mailto:ann@dementia-friendly.com)

Telephone: +44 (0)1431 821655

## Who are we?



In 2001 we (Andrew and Ann Pascoe) retired to Portgower in East Sutherland, in the heart of the rural Highlands of Scotland. Andrew was an Engineer in his old life and I ran companies, but in 2006 I became a dementia carer when Andrew was diagnosed with vascular dementia. Four lonely years later I decided no-one should ever have to do this journey alone.

Beginning as a lone 'Carer's Voice', I eventually founded our Dementia Friendly Community Social Enterprise and with a group of like-minded people am slowly turning East Sutherland from a county of little early dementia support into one that is a model of dementia excellence for both people with dementia and their family carers.

The purpose of my Fellowship was to research issues around early detection of both the symptoms of dementia and stress in carers of people with dementia, but more importantly how to red flag these issues and do something about it. These are important concerns, where better understanding and early intervention can make a huge difference to quality of life.

Andrew was diagnosed with vascular dementia at the age of 58. A year after diagnosis, I began receiving counseling from an Alzheimer Scotland support worker, but that assistance was based in Inverness (some two hours away), and required both me and the support worker meeting halfway at Tain – a trip that would not be possible for many rural carers.

However, after this support worker retired, there was no further source of one-on-one support available for me who remained Andrew's primary source of care. Initially Andrew's only support was visits from a CPN (Community Psychiatric Nurse) a couple times a year, but that too stopped a few years' back because he had vascular dementia rather than Alzheimer's. We now have no formal support and until such time as Andrew may or may not have another TIA (mini stroke) we will not have any further formal support.

Before leaving for Goa, I was quoted in The Northern Times, our local newspaper:

'... **T**his is a wonderful opportunity to share knowledge about dementia, an illness with a truly global impact. Last year I saw a paper presented by Dr Amit Dias from Goa in India. He talked about a community project created to bridge the gap between struggling families, a lack of local resources and overworked clinicians. The project also worked to raise awareness and understanding of the illness; vital in an area where diagnosis is extremely low and dementia is still seen as just another part of the aging process.

'**C**oming from a rural community in the Highlands, I saw very real similarities between our experience and that of the project in Goa. Could we improve our own dementia support through lessons learned in India? And could we share some of our achievements to help people with dementia and their carers?...'

## Where did we travel?

### Scotland to Goa - 8<sup>th</sup> May 2012

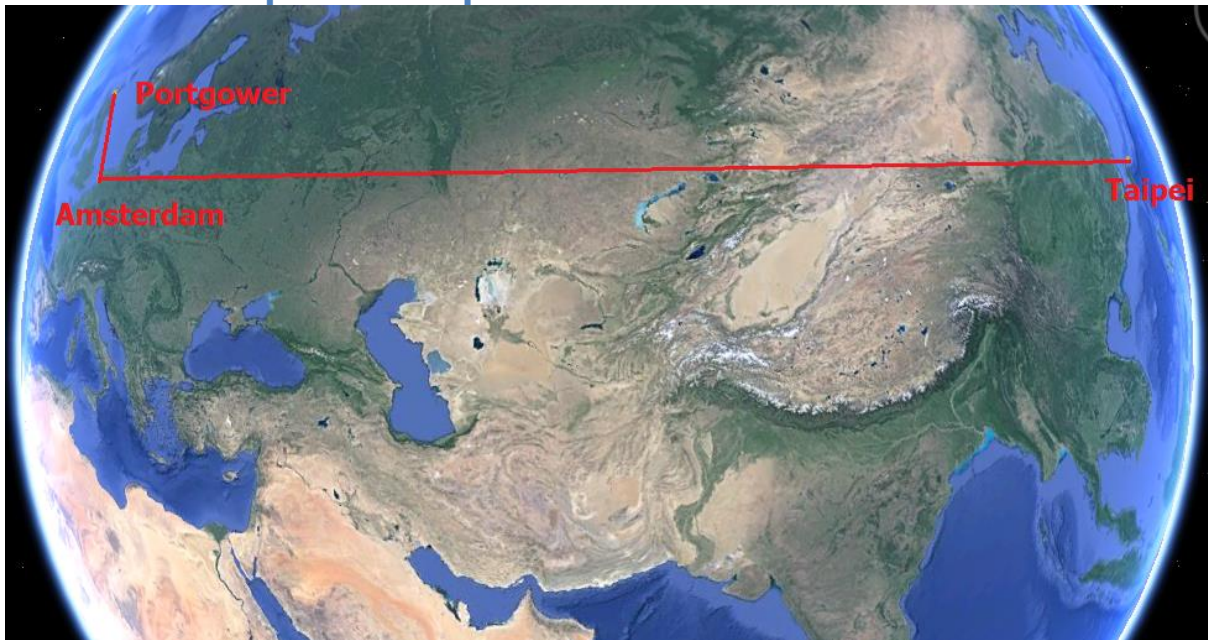


### Travel in India - first week of June 2012



### Return to Scotland - 15<sup>th</sup> June 2013

**Scotland to Taipei – 16<sup>th</sup> April 2013**



**Return to Scotland – 21<sup>st</sup> April 2013**



# Places/People Visited in India

## Goa

One of the key ingredients that made this trip so successful was the fact that in most ways we were able to emulate what we had at home i.e. a quiet house with a garden in a supportive community, near the beach and away from traffic and crowds. We found exactly what we needed in Colva, a tiny village about an hour from where I was to work, but it meant Andrew was able to quickly settle into our new home

...



I decided to do regular blogs of our time in Goa and Kerala – key ones below will give a flavour of the work I did in these two areas – which can be found in full on [www.acarersvoice.com](http://www.acarersvoice.com) . Andrew also decided to blog using his wonderful photography and these can be found on [www.adementiavoices.com](http://www.adementiavoices.com) , a new site we developed as a direct result of our time in India.



**And at last I got to meet Dr Amit Dias ...**

## Goa's Dementia Home Care Project

Posted by [Ann](#) on June 2, 2012

*Amit sent me this photograph saying I'd probably recognize it: and yes I did! It was him speaking in Toronto and I was somewhere in the audience with the brain buzzing and trying to figure out how I could get his project over to our Highlands. Amit put some notes together for his first blog plus pictures ... so here goes ...*



When Ann visited us she met Prof. Dilip Motghare, one of the authors of the original paper and the professor of the department of Preventive Medicine where I work and he was happy to note that she'd come all the way to exchange notes and learn. She also met the Dean of Goa Medical College, Dr. V. N. Jindal who is a neurosurgeon



and a strong supporter of the work carried out by me and my team in Goa. My dementia work is voluntary which means it is not really part of my job profile, but because of the support of my dean and professor I was able to implement this project and make a difference.

*And what a difference ... Amit's work will hopefully change our world too in the Highlands ...*

### The Research and Award:

Dementia affects 36 million people around the world (World Alzheimer Report 2009, Alzheimer's Disease International) and 3.7 million in India (the Dementia India Report, 2010). The Dementia Society of Goa which has been involved with developing need based services for people with dementia in the State of Goa. Together with my team I developed and evaluated a flexible stepped care intervention using non specialist health care workers to improve the quality of life in people with dementia and reduce caregiver burnout.

We got an International Award for our work in Goa and I was the lucky one to go and collect it in Greece.

The intervention won the International FMA-ADI award at the ADI conference in Greece in 2010 and was judged as the best evidence based psychosocial research for people with dementia and their families. The prize money is now being utilized for further dissemination of the research findings. The evaluation of the project was funded by the World Health Organisation through the Ministry of Social Justice and Empowerment, Government of India.

Ronnie Coutinho, the President of the Rotary club of Crosby, UK who has roots in Goa, happened to meet me through a Non Government Organisation that he volunteers for – Sangath. He was impressed with the work and the innovative idea and decided to support this initiative and make it available to all people in Goa. Encouraged with the results and progress of the project, Mr Coutinho and his wife Judy raised additional funds to support the project for six more months. Ronnie has now shifted out of the club in Crosby and the project funding will come to an end by the middle of this year.

#### **The team:**



**Amit (front left) and his dementia project team**

**Dr Amit Dias**, Asst Professor, Dept of Preventive Medicine, Goa Medical College and an active member on the managing committee of Sangath. Amit is also the secretary of the Dementia Society of Goa and the coordinator of the 10/66 dementia research group and the coordinator for the medical and scientific advisory committee for the Alzheimer's and Related Disorders Society of India. **Shezmin Jasani**, clinical psychologist is the Assistant Coordinator and is currently pursuing her MSc in Dementia Studies (at Stirling University) and **Lourdes Alvares** is the Home Care Advisor for the project. Lourdes is one of the four members of the team who provided the service in the initial project.

The project in its revised form was launched on World Alzheimer's Day, on the 21<sup>st</sup> of September 2010. Research in Goa had revealed that home based support can considerably improve the quality of life of people with dementia and address caregiver burnout. The services were provided free of cost. Everyone who approached Sangath or the Dementia Society of Goa, received the service through the project. We also extended the services to other frail elders such as those with Parkinson's disease and stroke. All participants received five visits on an average. Those people with severe dementia and those with behavioural problems were visited more frequently. Similarly more care was provided to those caregivers who were diagnosed to have more burnout on screening. Families received frequent telephonic calls to ensure compliance with the advice provided by the Home Care Advisor. The Project was also extended to old aged homes in Goa. Though old aged homes do not admit people with dementia, people do get the condition after admission. The services were extended to five old aged homes in the region.

Various workshops were held to create awareness among the community. I also carried out workshops for home nurses and developed a curriculum for them which has been incorporated in their course.

#### **Plans for the future:**

The team has started adapting cognitive stimulation exercises for the people with dementia in Goa. We intend to recruit more families with people with dementia on the project and try to improve their quality of life. More old aged homes will be included in the project in future.

#### **Significant achievements:**

The intervention provided through the project has gained international recognition and the Project Director was invited to International conferences on Alzheimer's Disease in Havana in Cuba, Salamanca in Spain, Bangkok in Thailand and Toronto in Canada to share the research findings and look at the possibility of adapting the intervention to other regions.

I also received a research fellowship to visit the center for excellence for Alzheimer's Disease research in Perth to work under Prof Ralph Martins a leading expert in the field of Alzheimer's Disease. My team also saw a real need to integrate the services with the existing primary health care services available in the State of Goa. To do this I contributed to the National Dementia Report - produced by the Alzheimer's and Related Disorders Society of India – which was handed over to the Government of India to help them develop a National Dementia Policy.

*In Scotland we have an excellent 5 point Government Dementia Strategy. What we have to do is ensure it reaches grass roots i.e. people like Andrew and me ... and hopefully by adapting Amit's programme to what already exists in the Highlands, we'll bridge the gap which will go a long way to doing exactly this. So thank you Amit for talking in Toronto that day!*

## Sneha Mandir Old Age Home ... Goa, India

Posted by Ann Tuesday, 15<sup>th</sup> May 2012



One of the twelve cottages comprising the home ...

Today Shezmin and I visited Sneha Mandir - an Old Age Home situated outside the town of Ponda about an hour (on the back of a scooter) from where we live ... there are no specific dementia care homes in Goa ... which is run by the Goa Hindu Association Trust and has just celebrated its 30<sup>th</sup> anniversary. It is a secular institution, an NGO (Non Government Organisation) which is supported monetarily by members, donors and 'well-wishers' totaling some 2,500 in number.

The Home itself is situated outside the town of Ponda in beautiful grounds. It comprises twelve cottages - started off with just one in 1982 – with three or four shared bedrooms per cottage (some for married couples too) supported by a central block to encourage interaction and camaraderie amongst residents and make them feel part of an extended family.

The central block has a dining room with kitchens, two television rooms (one for men and one for women because generally men and women like to watch different things – have we thought of that???) a library and a lecture room plus of course wonderful gardens, even a waterfall (manmade!).

In total there are 85 beds supported by 12 trained nurses (in white) and 12 Care Helpers (in blue) on a 24 hour rotation basis (3 batches of 4 nurses/4 care workers per shift) from 9am-6pm and 6pm-9am, with 6 days on and 1 day off each week. Over and above this there are 9 administrative staff plus 6 kitchen staff and a full-time gardener.

The manager (right) ... Alka Tai (Alka is her name and Tai is her title of respect meaning 'elder sister') ... so generous with both her time and knowledge ... I gave her a thistle bag with heather and she started to eat it! In India they have bags holding a kind of tobacco ... I had to explain it was for her clothing drawer...



There is also a Geriatric Centre for bedridden patients (approximately half the beds at Sneha Mandir) with a physiotherapy and surgical centre (open also to non-residents in the area), a yoga instructor, a mobile clinic and ambulance service (serving 8 villages in the area) as well as a Home Nursing School (funded by the Goa Government) which provides free education to 20 nursing students a year, on the proviso that their practical training is done at the Complex.



Waterfall into the pond outside the dining room ...just so lovely ...

Making chapatti ... you can't buy it here ... it's always made in the home from fresh flour ... first rolling out a ball of flour paste into a thin circle, then cooking it briefly in a frying pan, then on an open flame for a minute to get the 'bubbles' ... they were so good, I had a taste and then promptly ate three!!!

I thought the most interesting innovation was how the community is encouraged to interact with the Complex. The Complex supports the community e.g. by adopting children in high school (at present 100 students) and providing them with books, uniforms, fees etc. as well as tuition and guidance in various academic fields. If any of the students show potential for further study, that further expenditure is met by the Trust.

In turn students spend a lot of time with the residents. They become the family who is not there. In fact when we visited, there were a group of 5 or 6 young people simply 'visiting'. It was so good to see! Music groups, clubs, voluntary groups, dance groups etc. are also encouraged to 'visit' and people doing interesting stuff often offer or are invited to lecture to the residents ... all in an effort to make a family environment and a busy day for residents.

Another interesting aspect is that all the residents are encouraged to use their skills e.g. if they used to cook, they are welcome in the kitchens; if a resident was an engineer and something has broken, he is first port of call; gardeners help the gardener and managers or clerical staff even help in the admin section: residents are made to feel useful and part of a family.



One of the care workers ... the word 'serene' kept coming to mind ...

Indeed their motto is 'home away from home'. In India children by law are required to look after their parents and so the only reason elderly people need a shelter like Sneha Mandir is because:

- Their children are working/living abroad (and when the families return, more often than not, the elders go back home)
- The resident is unmarried and has no children
- The children have abandoned the parents, but in thirty years, this has not once ever been the reason for admission.

Shezmin and I have been invited to stay at Sneha Mandir this weekend ...

## Guests at Sneha Mandir ...

Posted by [Ann](#) on May 20, 2012

Yesterday the power and water went off at 8 in the morning and was off all day, coming on only at dusk just as we prepared to close doors and windows against mosquitos and set up candles and torches for light. We later discovered everything had gone off because the city was doing its annual preparation for the monsoons heading our way. The temperature, with no air con, no fans, no cold showers, no cold fridge or iced water and high, high humidity felt as if it was in the high 40s, so it was quite a shock to discover Colva temperatures were low 30s compared to 40s elsewhere in India. Welcome to the heat!



And guess who spent the previous night at Sneha Mandir in exactly the same conditions: no air con, no iced water, no cold showers ... only an open window but no breezes.



**Spartan, functional with only a net between us and the mosquitoes ... and any breeze there might be ... or not be!!!**

It felt so hot during the night that poor Shezmin and I pushed our beds as near as possible under the one fan above and prayed the power wouldn't go off during the night. I vaguely woke up at one point and saw Shezmin standing instead of sleeping ... and next morning she said she'd been trying to get nearer the fan! And she lives in this part of the world!

Spending a night in an Old Age Home before your time is due, is an eye-opening experience and I came to the conclusion that if that is where I have to end my days one day, then my fondest hope is that wherever I might land up, it will be like Sneha Mandir i.e. a home and not an institution.





**Exotic corners of Sneha  
Mandir's beautiful garden...**

From the moment we arrived, I felt we were guests in a family home with Alka Tia (Elder Sister) our gracious host ... not just a manager ... whose only wish was to welcome us into her charming home ... and her garden, which of course I absolutely loved. As clearly did the residents who used the lovely areas dotted around for. But I think what I loved best was how clear it was that this was everyone's home, that the residents were just as welcoming, that it was a resident who called us to supper, another one who took us to the serving area to choose our food and yet another resident who hovered to replenish plates as they emptied.



**This was our breakfast: curry and rice  
cakes ... I didn't get the recipe ...  
carried out by then...**

And although none spoke English, I felt the warmth and welcome.

We had time to explore the Complex properly and quite by chance found a huge lecture/classroom upstairs with obvious signs of 'things' residents did when they had visitors: paintings done together with children;



Paintings done with the children...

clay models and glass painting, sewing and musical instruments and books strewn all over. I could only close my eyes and imagine these groups all working together as a mother would with a daughter or a grandfather with a grandson ...

And the next morning we got up early to do our yoga! And no, our legs didn't get all tied up in knots (as was predicted by some ...) but the thing I did notice is that it was 7 in the morning and half the residents were up and dressed, hair groomed, beautiful saris, and most importantly, everyone was there because they wanted to be there: everyone felt motivated enough to get up and get dressed and be ready to start their day. It was quite remarkable to see ... The yoga was gentle with exercises to move every part of the body, including getting the brain going!! Plan to practice those regularly ... with Andrew too!

So in all, an extraordinary experience and one that will stay with me for a long time to come!

The words that come to mind are serenity, graciousness, dignity, kindness and above all home ... it felt like home from home ...



A quiet corner to sit and reflect ... found lotus lilies in the pond and how I wished Andrew was there with his camera...

## Sangath ...

Posted by [Ann](#) on May 22, 2012



Spent the day yesterday at Sangath with Jothees – Martin Prince's PhD student – and I have to say my brain is being well and truly stretched!!

I hope to help Jothees in one tiny section of his work on 'decomposing' caregiver stress interventions and outcomes ...all riveting stuff ... and so incredibly logical once you understand it ... I hasten to add am still in the process of fully understanding it all ... keep rereading bits of the REACH paper ... To summarize:

- Jothees has taken all the literature available on caregiver stress interventions and outcomes
- and is using a bio-engineering technique that focuses on the process of mapping each intervention on to a conceptual framework to understand the link between intervention and outcomes,
- Jothees' PhD work is to actually make the link and do it! The Nike way!
- This means that when this is done, we should have a true blueprint to intervene in any caregiver stress scenario.

I also had a chance to talk with other staff members at Sangath regarding their projects (covering all areas of health: children at school and at home; young mothers – by our standards, still an incredibly high mortality rate in childbirth in rural areas where culture and language difficulties play such a devastating role; babies; the elderly; and the frail) and what I find so interesting is that here they too have come to the same conclusion I did: if we do not have the resources to provide the perfect care with professional/clinical people etc, then we have to go the next route which is to train lay people to spot the problems and refer them on to those professionals for action.

Again this is so logical to me ... and in the Highlands I have had such resistance to this: I say we, people with dementia and their caregivers, need help, any help, even if it is just a stepping stone ... they (the professionals) say we have to wait till the resources allow them to come to us and do it properly. And I say I'll be dead by then! That I simply do not have the patience to wait for that eventuality (them coming to me or me being dead...)

NDCAN (National Dementia Carer Action and Networking) ... (I have a colleague on this group who always imagines us running around wearing activist balaclavas ... and I've said mine will have to have an elephant on it to represent my 'Indian' connection ...) is meeting with Nicola Sturgeon, the Scottish Government Health Minister, on 31st May and although I cannot be there, I've asked that my question be put to her: *why does the national strategy NOT reach us at grass roots in rural areas i.e. why are services different in different areas ... and what can we do to change this.*

I'm thinking that if her department works 'downwards', we will work 'upwards' and hopefully we can try and meet somewhere in the middle!! Let's see what she says...

Today I'm home, thinking/writing about Jothees' work: we have a Sangath orientation tomorrow at 10am and then Jothees and I will work in the afternoon. Amit and I have also begun working on a possible strategy to get caregiver stress red flagged, monitored and dealt with in the Highlands: told you: this old brain is being stretched!!!

And Andrew was out early this morning capturing life on our street: he's sitting right here working on his blog and also putting together a photo record (slide show for computer or tv) of our time here. He's captured some incredible pics ... from stray puppies and pigs in the coconut fields to families cleaning their teeth in the sunshine ... it's starting to look really good!

## Visit to Taliegoa Heath Centre ...

Posted by Ann on May 25, 2012

Loss of inhibition, sleep deprivation, falling, confabulation (forgetting what happened and making it up, but convinced it is the truth), forgetting to eat, incontinence ... these are all issues in elderly people that can lead to enormous family caregiver stress. They are of course also signs of dementia.



If these symptoms can be addressed early on, there is an excellent chance that the progression of dementia and the problem behaviours associated with it can be delayed, the person will be able to stay at home longer and the caregiver will not only be better able to cope, but also have reduced stress.

A classic preventative intervention, for example, is if a pattern of sleep disturbance emerges in an elderly person, the person can be encouraged not to sleep during the day, to perhaps do more physical exercise and in extreme cases be helped with medication. Patient sleep is improved, caregiver stress reduced.

Or if a person with dementia seems to be telling fibs (or sometimes even great whoppers) the caregiver can be taught it is not because he is doing it on purpose, but more likely that he has genuinely forgotten what happened and just made it up as he thinks it happened. And truly believes it. Once the caregiver understands this and is taught how to deal with it, carer stress reduces.



This is the stress poster ... we should have them everywhere ...

But these things need to be detected early on. Bearing in mind the vast population and the decided lack of professionals, Goa has around 25 primary health centres each supposed to be serving 30,000 people, two district hospitals (one in the north and one in the south) and a tertiary health care hospital which is the Goa Medical College.



**In the classroom ... one-on-one role playing with one of the Health Workers ..**

Each primary health centre has sub-centres with Multi Purpose Health Workers (MPHW) who do home visits and provide support to the area designated to them. They are non-specialist workers and it is they who do home visits, identify the problem, treat what they can and pass only critical cases on to the professionals. The medical doctors visit the sub-centres once a week for immunization and to run the clinics.

Yesterday at the Taliegoa sub-centre, I saw how role playing is used first to teach the lay health worker to assess potential problems, then how role playing is used to keep them current and updated.

Since policy makers are interested not only in management, but also prevention, the whole Goa medical system revolves around early detection and prevention of serious illness. However, till recently the focus was generally on infectious diseases. COPE (Care of Older People) is a programme being piloted in Goa by Jothees under the guidance of Prof Martin Prince and Dr Amit Dias. The idea being that if you prevent falls, there's less likelihood of, say, fractures, severe injury and disability; if you prevent strokes, again cognition problems could be prevented as in vascular dementia; the same applies to nutrition and mobility. So by detecting frail elders earlier on, we can intervene early and prevent a crisis from occurring.

The sub-centres deal with all aspects of family health, from conception to contraception, from birth to death, including all illnesses like malaria, leprosy etc., but it's become apparent in recent years that caregiver stress plays an enormous role in family affairs: and increasingly so as the ability of the family to look after frail elders is decreasing.

Traditionally every member of the family had his or her place: the father went to work; the mother kept the home; children helped at various stages; and grandparents helped until such time as they needed caring for themselves. But the family lived together in one house. Now it is changing: families are going further away to work or study, elderly people are left alone, children are at school and so often the burden of care falls on the shoulders of one person.

Transport is also a problem ... same as our rural areas ... no transport for the elderly to the Centre and difficult for doctors to do home calls. Sometimes the Health Worker simply puts them in his car or on his scooter and brings 'em in...

Take Caregiver Arjun (age 40ish) who was married. He and his wife lived in his mother's home with his unmarried brother who has learning difficulties. For ten years or so, Caregiver Arjun worked while his wife took care of the family and house according to tradition. All was well until his mother developed dementia. With hindsight all the signs were there: repeated falls, memory loss, confabulation, incontinence etc., but they were not recognized and nothing was done. Eventually caregiver stress for the young wife was too much and she left taking the children with her.

At first Caregiver Arjun (the husband of the departed wife and son of the person with dementia) stayed at home to look after his mother and brother, but was eventually forced out to work because they needed money to survive. So Caregiver Arjun now works as a community health worker in a nearby primary health centre and is one of their best for the very simple reason that he has been on that journey himself!

This is his day job. His night job continues to be caregiver for both his mother and brother who are alone during the day when he works. So, like all caregivers around the world, his work week is 168 hours/week.

Confirming again that no matter where you live, caregiver stress is the same, with the same devastating results on families ... And that early diagnosis and early caregiver support is essential.

## Thoughts about Stats

I was thinking about stats this morning. Jothees gave me the astonishing figure of a 1.2 billion population figure in India with 3.7 million diagnosed with dementia. Amit confirmed this, adding that only 8.3% of the total population is over 60 (according, I should quickly add, to the 2001 Census) with the prevalence of dementia in India at 1.9%. So I asked Peter to check out some figures at home:

- our entire Scottish population (2012 Census) is 5 million ... versus 1.2 billion in India ... gulp!
- with +60s at 22% (versus 1.9% in India)
- with 84,000 dementia diagnoses in all of Scotland (versus 3.7 million in India)
- and 4,000 in the Highlands.

As in Scotland, the Indian figures are set to double and treble over the next decades ... again confirming why the work being done here is not only essential, but also ground breaking ...

I was also intrigued to learn from Amit that all medical care at their Goa Hospital is free for everyone ... and that would include us, which was mighty impressive!



**Proof training can be fun ...  
especially role playing with  
Jothees ... think we should clone  
him and bring him home to!!!**



## Kerala

Posted by [Ann](#) on June 3, 2012

This is our little taxi ... you can just see the black bonnet ... hemmed into traffic between buses and trucks ... you can barely see the sky ... and all of this at 40 mph ... I closed my eyes most of the time ...



The airport was slick and modern ... something I really didn't expect ... and Cochin itself a huge sophisticated city with people and billboards and cars and scooters and more people and shops and high rise buildings and more people on every inch of land and on the roads, but there are also the outlying villages.



The next day I visited ARDSI in Cochin and joined a training workshop for managers of Care Homes and Senior Citizens Associations (Age Concern) and was fascinated how it was formally opened with prayer and a candle lighting ceremony.

To accommodate all the religions, a moment of silent prayer is held at the beginning of most anything ... today it was the training session and in keeping with tradition I was asked to light the candle ... really quite solemn and moving ...

The speakers included a psychiatrist, a homeopathic doctor, nurses and people from ARDSI (equivalent to our Alzheimer Scotland) all giving practical information regarding dementia itself, but what also intrigued me was how the emphasis of the training also always included the caregiver ... in fact the paper I gave was a version of the 'Learning from Caregiver Mistakes' from Warsaw last year.

Over the week I worked with many students, both Home Care lay workers and MSc nursing students ... and was amazed at the depth of questions they asked and their understanding of caregiver stress: their levels of compassion – and common sense – were obvious and it was a joy working with them.

The workshop was held at the ARDSI Centre which also hosts a day centre for people with dementia: four workers to 10 people with dementia. This is the first Dementia organization started in Kerala by Dr Roy who is now the Alzheimer's Disease International Chairman.



**I also met Dr Jacob Roy and his staff at ARDSI in Kunnamkulam and visited his Tropical Health Foundation which cares for the disabled and the elderly - and was given a traditional bird carving from that area.**

## Cochin Care Homes ...

Posted by [Ann](#) on June 3, 2012

I visited the famous ARDSI Cochin Harmony Home and again was struck by the feeling of home from home ... so different to our more institutionalized homes. This is a bedroom looking out on to the groves of trees. Such emphasis on gardens here ...

Staff and people with dementia interact all the time, with a wonderfully touchy huggy style, much laughter and even a freedom ... because of the hot weather, the gates of the property – rather than the doors of the house – are locked for safety and everyone, including the people with dementia, are free to wander around the huge gardens and all over the house: exactly as they'd do in their own family home.



**Sarji John ... the manager of the Harmony Care Home ... and his smile is indicative of all his staff. No wonder it rubs off on the residents. We sat outside before lunch chatting to all the people and I was delighted so many of them remembered English, one woman in particular who had been an English school teacher. She eventually complimented me on my English and wondered if we'd been to school together!**



**This is Cochin Harmony Home, one of the few homes only for people with dementia. While Old Age Homes are plentiful, there does not yet seem to be a proper awareness of dementia ... it is still regarded rather as normal forgetfulness in the elderly.**

Again I think of that man in the BBC Panorama programme from Phoenix and remember how desperately he wanted to open the doors and just go outside for a walk and feel his toes in the grass ...



Then we visited a palliative care Catholic hospice for cancer patients. In total 4 Sisters – together with 10 trained nurses – ran the wards and while many of the patients were bedridden, those who were not, mucked in and helped with the chores, making everyone feel useful. It was quite an eye-opener.

The wards are so big and wide and airy with the perfume of incense pervading all - the whole building gives off such an aura of peace and tranquility.

John Sarji and Sister Mary Valsa, the managers in these two places, were also so generous with their time and experience and answered my long list of questions. Will do detailed reports of both these visits ...



**The palliative care hospice run by nuns. All the rooms, including the passageways, are so big and wide and airy with the perfume of incense pervading all - the whole building gives off such an aura of peace and tranquility.**

## Santhiniketan Old Age Home ... Kalady

Posted by [Ann](#) on June 7, 2012

In Kerala I also visited the Santhiniketan Old Age Home in Kalady outside of Cochin. This is the grand entrance. We arrived in the monsoon and were soaked just running from the car to the building. Looked like a drowned rat, but the sun came out a few minutes later and we dried up in no time! Thank goodness for the flip flops ... which you leave at the door ... you never wear shoes inside any building ... and I keep wondering if they'll still be there when we come back out again, but they always are!



Babu asked if I wanted to take all the workers back to Scotland with me ... I said YES!!!



High glass ceilings for light ... the meeting was held in this area and we could hear the monsoon drumming down on the glass skylight! And hear the thunder ... and see the lightning! Residents' rooms lead off these wide corridors which means they can sit chatting here when the monsoon precludes walks in the gardens.

There were about 50 residents of all ages waiting for us and what struck me so forcefully was again how cheerful and happy everyone seemed to be! Smiles from everyone ... the residents and the staff alike. And again beautiful gardens, huge airy open rooms and freedom to roam and do just about what they like when they like with whomever they like. In one corner, school children were laughing with residents, in another staff were playing a board game with residents and in yet another a group of men were solving the world's problems while alongside them a group of woman were chatting. No regimentation and no strict rules ... home from home!

Babu Varghese (ARDSI – the equivalent of our Alzheimer Scotland) was there to tell them about dementia – part of ARDSI's awareness programme. ARDSI has a mammoth task ahead of them: there are over 100 care homes in Cochin City alone with anything up to 100 residents in each and dementia is not anywhere on any radar. Most are privately run i.e. fees from the families (again most are away working or studying) and the residents have their own doctors. So to intrude and try and set up memory clinics or dementia programmes can be seen to be invasive.

However, by talking to the residents reasonably regularly, the idea is to remove some of the stigma about dementia and encourage the residents themselves to ask for a memory test.



A team of a dozen Health Care Workers was also present and after the presentation I noticed that each one took time to talk to a resident and used the time to get to know the person, at the same time giving that person the confidence to open up and talk. And my goodness talk they did. Again dementia was not the only subject discussed and many other issues around 'getting old' were raised by the residents

One man delightfully piped up 'ignorance is bliss', everyone laughed and then settled down to listen. Of course no-one wants to hear about dementia, but when I piped back 'two reasons for having an early diagnosis is that you can tell you loved ones what your wishes are e.g. that Andrew's wish is that as his dementia progresses, he still wants to 'do' things like going places and his photography, not be sat in front of a television all day ... and the second one is that you can get your financial affairs in order.' Then they sat up and listened.

Interestingly it is the eldest male of the household who has total control of the family ... his wife, his children ... even his grown-up children, specially his daughters. Imagine the problems that arise if he develops dementia? And only if the father agrees to a love marriage instead of an arranged one can it happen. I asked my taxi driver (mine of information these men!) if most of his generation have arranged marriages, doesn't anyone ever 'fall in love' in India? This he said is what is now causing major problems: when wives stayed at home in the old days, they never met outsiders to fall in love with ... but now that family finances require the wife to work, she is meeting those outsiders and 'falling in love', resulting in families breaking up and society dramatically changing.



Modern Cochin City ... in such contrast to Colva where we live ...

## At last ... Kunnamkulam and Dr Roy ...

Posted by [Ann](#) on June 9, 2012



At last culmination of the journey from ADI London where I met Dr Jacob Roy – India’s ARDSI Chairman and Alzheimer International Chairman – to his offices in Kunnamkulam where it all began in India. Dr Roy is a Pediatrician, but got caught up in dementia when his father developed Alzheimer’s and Dr Roy became his caregiver. So we had a lot to talk about ...

Dr Roy has invited me back to spend more time at the Harmony Care Home in Kunnamkulam ... similar in set up to the one I visited in Cochin, but of course it was the very first one in India.

## **Back to the Scottish Highlands**

**I came away from India with the strong conviction that:**

- **carer stress needs to be addressed in rural areas;**
- **perhaps the community is the place to start; and**
- **we have got so caught up on safety and protection in our Care Homes, that we have forgotten the 'home' part of Care Home.**

**And so began the work for change ...**



## Alzheimer Scotland

**Alzheimer Scotland gave me support as a carer when no other support was available in East Sutherland ...**

Reflecting on my experiences while in India, I recalled hearing Henry Simmons, CEO of Alzheimer Scotland, speaking about the key challenges identified in Scotland's first National Dementia Strategy:

- about the **fear** of dementia,
- and how the betrayal of **respect and dignity** for dementia families was probably the single most important reason why there was fear of dementia and why the stigma was so profound
- about the lack of **information and knowledge**, and
- how the general health and social care services didn't always understand how to **support** dementia families;
- but the chord that really resonated with me was when he had talked about the need to **teach Carers** that we too had rights, that we too needed help on this dementia journey and that we were truly an integral part of our loved ones' care.

I remember sitting there riveted, thinking 'goodness someone knows how we feel out here'. And I must admit I went home and waited for the Strategy to filter down to us up in my beloved East Sutherland. It didn't take too long of course to realise that was simply not going to happen and that since Andrew and I didn't have the luxury of time to wait for it to reach us, what was I going to do to hurry it up?

After studying the Strategy I'd also discovered to my astonishment that besides addressing those key issues around dementia itself, the Strategy was absolutely enshrined and underpinned by [basic human rights](#). Basic human rights that Andrew and I as a dementia family were entitled to. And it also became very clear to me that those at the top knew exactly what we needed down here at grass roots ...

In October/November 2012, Alzheimer Scotland in conjunction with the Scottish Government held [Dementia Dialogues](#) around the country. I addressed two of the Dialogues, one in Inverness and the other in Fort William.

## NHS Highland

**NHS Highland was the catalyst for my Churchill Fellowship to make change in the Highlands and was the backbone for all my work ...**

Within days of returning to Scotland, Elaine Meade, Head of NHS Highland, who had been reading my blogs, invited me to speak at the forthcoming NHS Highland Annual Event in September (view [paper](#) and [film](#)), giving me a magnificent platform to launch my assault on the Dementia Strategy, i.e. working to get it down to us at grass roots.

And before that I was asked to address the NHS Annual Strategic Planning Network Conference in August (view [presentation](#) and [notes](#)) intended to 'influence, drive and develop' their national health planning agenda.

In a half hour paper, I presented four case studies, the last one around dementia and how we were struggling in the remote rural areas. NHS listened. They really listened!

And today they are the backbone of all the work we do around our dementia friendly community work (see below).

## Crossroads Caring (East Sutherland)

**Crossroads Caring in East Sutherland was the vehicle for testing change ...**

Also shortly after returning from India, I worked with Crossroads Caring (East Sutherland) and together we proposed how using Crossroads' Care Attendants as the flag raisers for early dementia signs as well as carer stress could be viable (view [paper](#)). While there has been interest in the programme, to date we have not found funding.

However, as a direct result of this work, a Task Group is working on 'Prevention versus Crisis' with the intention of supporting dementia families earlier rather than later.

## Websites

**'... Isolation is a word that resonates throughout the journey of dementia: at the beginning when you don't know which way to turn and also along the way as everything changes around you.**

**Our particular journey was so lonely, so painful and so isolated by our rural location that I decided no-one should ever have to do this journey alone. Today I am not alone and the fact that I am speaking here at an international dementia conference in Taipei is testament to the power of the website. How did this all happen ...'**

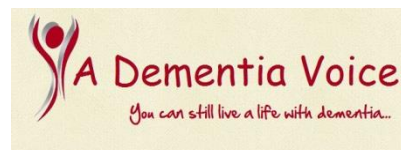
And so began my paper at the Alzheimer's Disease International Conference in Taipei in April 2013:

- Power of the Website Voice (view [presentation](#) and [notes](#))



The first website we established was **A Carer's Voice** [www.acarersvoice.com](http://www.acarersvoice.com) which I used for blogging from India.

This site has continued to grow and directly from it was born **A Dementia Voice** [www.adementiavoice.com](http://www.adementiavoice.com) so that people with dementia could also blog.



Next came **A Care Home Voice** [www.acarehomevoice.com](http://www.acarehomevoice.com) using the fictitious Sunset House to voice the reality of living in a care home.

Finally **Dementia Friendly Communities** [www.adementiafriendlycommunity.com](http://www.adementiafriendlycommunity.com) was developed as a vehicle for our dementia friendly community social enterprise, but also as an umbrella site to hold the different voices.



# Dementia Friendly Communities

**Once I heard the magical words *dementia friendly communities*, it took little time to realise this was the vehicle we needed: that if as a community we could *push upwards*, we would have a far better chance of meeting that Strategy *coming down*.**

**Recognising this urgent need, together with a few like minded people, I established a Dementia Friendly Community Social Enterprise with the simple aim of recognising and embracing the challenges a life with dementia presents to the families affected and enabling them to live life to its full potential.**



In under a year, the Enterprise has grown in strength, taking significant steps to raise the profile of dementia and draw together strong support. East Sutherland is now well on the way from being a community with little dementia support to one that is striving to be a beacon of dementia excellence. Successes include identifying local talents and resources within the community, building strong coalitions and raising awareness of what a dementia friendly community means for dementia families.

By speaking out about dementia the Enterprise is turning our rural community into a dementia friendly one by bringing the Scottish Dementia Strategy down to grass roots and making a real, lasting difference to individuals, families and the local community. Above all we are relevant and informed by the people we are committed to help.

## How did we do this?

- **Developing Strong Networks and Partnerships**

The Enterprise identified local assets: people with influence, skills, strengths, enthusiasm and talents. We then made strategic links with the Highland Council,

NHS Highland and Alzheimer Scotland to seek support and draw on their contacts and influence. Their response was, and continues to be, practical and very encouraging: we ask and they do!

We have always been very clear that our work has to be informed by the people we have set out to help. So, in partnership with dementia families, we developed our Collaborative which now has 18 partners, including local agencies, service providers, voluntary groups and businesses. All united by a shared vision for a dementia friendly community for East Sutherland.

- **Promoting Awareness**

A steering group drives the work with actions progressed using task groups, one of which was to develop a dementia friendly community identity. NHS Highland made a [short film](#) to mark the inaugural meeting of the Social Enterprise which got a premiere viewing at NHS Highland Annual Event last year, attended by over 400 people and watched by another 600. I was also invited to speak at the event.

More positive coverage was given in NHS Highland News – a newspaper distributed to households across Highland and the Enterprise is now working with our local newspaper to run a campaign to further raise awareness to make all businesses in East Sutherland dementia friendly.

- **Providing Practical Help**

Local Community Centres also support dementia families to be *engaged with* rather than *isolated from* the community. They run a range of socially inclusive activities (see example in the [recent presentation in Taipei](#), slides 32 to 34) such as indoor bowling and Tai Chi in Helmsdale. This is one example of local opportunities for people with dementia to take part in their chosen activities for as long as they wish.

Last year an event was run which brought local people together including local school children for a community fun day. This year a [Parisian Ceilidh](#) was held with nearly 150 people from across the county enjoying singing and dancing, a pamper parlour for carers, a quiet room for those who needed it, a bustling Parisian bistro for lunch whilst also providing practical support and information in a dementia friendly setting.

An in-depth evaluation of this event is in progress and will confirm that the way to go is to arrange socially inclusive community events rather than dementia-ghetto type activities exclusively for dementia families. This is of course over and above peer-to-peer support that is also so essential.

- **Addressing stigma and discrimination**

The work of the Enterprise also focuses on increasing empathy for dementia families by speaking out about the practical and emotional challenges they face. The Awareness Task Group is building an Awareness Tool to provide awareness raising

for staff in local businesses and organisations. Members of the Awareness Task Group have been trained to deliver this session to open the door to receiving more in-depth training - when and if organisations want it - from the professionals.

By doing this work, our rural community is slowly turning from one with little dementia support into one that is fast becoming a model of excellence; one where Andrew can be part of the community rather than feel isolated from society.

Visit the [Dementia Friendly Communities website](http://www.adementiafriendlycommunity.com)  
[www.adementiafriendlycommunity.com](http://www.adementiafriendlycommunity.com).

## Dementia Friendly Communities Collaborative

**We now had to make sure our work was informed by the people we had set out to help.**

In partnership with dementia families we formed a [Collaborative](#) with local agencies, service providers, voluntary groups and businesses who shared our vision of a dementia friendly community.

Together we identified people of influence in our community who had the passion and potential to be dementia capable community leaders. We engaged with them around the dementia agenda and built on the skills, strengths, interests and enthusiasm that people already had. And it's amazing how many we actually found in our rural community.

# Task Groups

**The task groups make our dementia friendly visions become reality ...**

A key early task was to begin to ensure that people who worked and lived in the community had a better understanding of dementia and how to respond to it. We developed a short dementia awareness raising tool and needless to say soon learned there is no such thing as 'ten minute training': what we did discover however was that this initial awareness education would be the introduction to further dementia instruction from the professionals. What we did was open the door.

Other task groups are working on issues around (see details of the task groups in a [presentation given in Taipei](#), slide 25):

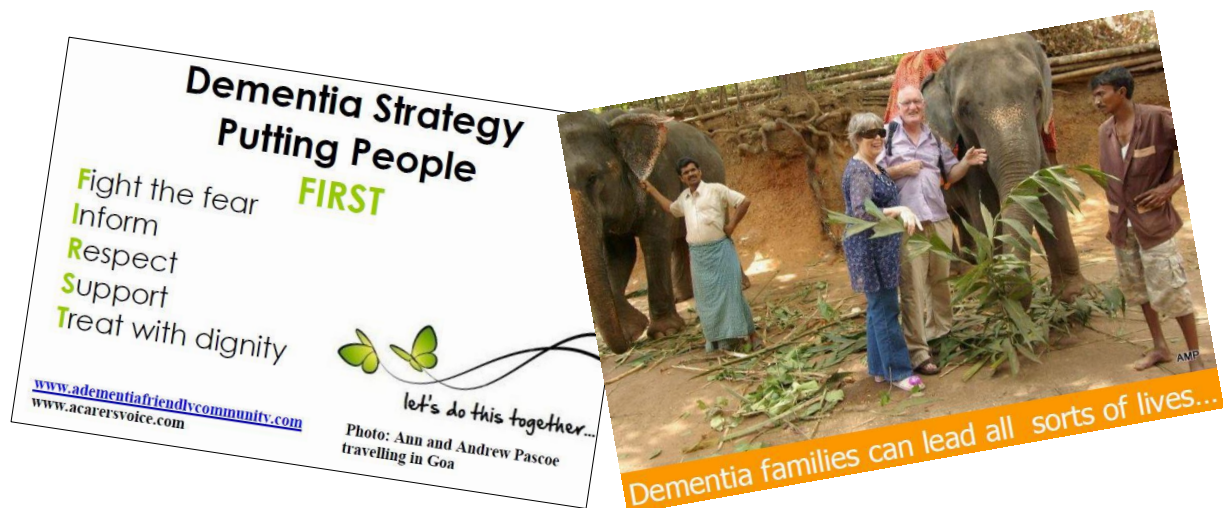
- Promoting our dementia friendly community
- Reducing dementia isolation
- Changing the crisis ethos to one of prevention
- Complementing the work we do directly in the community with a series of online resources
- Putting local Care Homes at the heart of the community
- Promoting telecare services so essential in our remote regions
- Working with our local newspaper - delivered to 97% of residents in our rural area – to make all businesses in Sutherland dementia friendly
- Celebrating the 2014 Commonwealth Games in Sutherland: a project to allow our socially inclusive community - including dementia families - to share in the fun of all of the Games ...

# Education

**Education and Knowledge  
have to be at the very heart of  
changing the system ...**

The key to changing society's perception of dementia is education and knowledge. With knowledge we as carers can be prepared for the journey ... and with knowledge, people with dementia can better understand what is ahead and what they can do to make it all a little easier for everyone.

As a community, armed with knowledge, we can better empathise with and support dementia families so that they too can live a life at home doing the things they want to do when and how they want to do it. I worked with the NHS to produce the following postcard:



To this end most of the work I do outside of the social enterprise is lecturing or workshops to help carers better understand coping strategies for living with a person with dementia:

- as a member of Alzheimer Scotland's [NDCAN \(National Dementia Carers Action Network\)](#) my work is predominantly around education:
  - NES Dementia Carer Educational Resource (to be published shortly)
  - Dementia Champions ... ongoing work
- As an MSc (dementia) student at Stirling University:
  - carer workshops setting out coping strategies ... view [presentation](#) and [notes](#)
  - module on carer coping strategies for Stirling's 3<sup>rd</sup> nursing students
- Crossroads Caring East Sutherland:
  - [Dementia programmes for Care Attendants](#)



# Taipei

## I'm in Taipei ...

Posted by Ann on 15<sup>th</sup> April, 2013

My goodness, have arrived in Taipei which is the capital of Taiwan - originally Formosa - and on the map it's a big island that sits to the right of China a little below Japan ... so have flown across lands and oceans not yet crossed before. Mr Churchill, you have certainly taken me to new worlds: this is the last part of my Churchill Fellowship and I'm here in Taipei to present papers at the 28th Alzheimer's Disease International Conference.

Arrived at the airport yesterday and quickly realised all the officials were wearing face masks, so had to wonder if they knew something we didn't. I keep thinking about that man up to the north of here who has his finger poised over the nuclear button and hope all these people down here realise that face masks aren't going to help them much if he does get to press that button. But to happier things: wonderful lush green vegetation on the drive in from the airport, it's



This is the second highest building in the world ... called Taipei 101

warm ... 24 degrees today ... and sunny and I can see the mountains from my hotel room. Also Taipei 101 which is reputedly the second tallest building in the world.

Will have to go check this all out later. Right now am trying to get used to the seven hour time change

...



View of the mountains from my room on the 20th floor ... some high buildings around here!

## ADI Conference ...

Posted by [Ann](#) on April 22, 2013



My Churchill Fellowship story ... can't believe it was nearly a year ago we were heading to Goa and Kerala ...

And my two buddies in Taipei: Jim Pearson from Alzheimer Scotland and Jeremy Hughes from Alzheimer's Society in England and what great discussions we had. Jeremy did a brilliant overview of the dementia friendly community work being done in England, especially the work around dementia friends ... something we really need to look at ... England took the idea from Japan who now have 4.something million dementia friends: all it entails is 45 minutes of awareness work with groups of individuals (we could probably use our existing awareness tool to train trainers to train groups!) with annual self-assessment to ensure awareness is kept up to date.

So at last we were into the nitty gritty of the Conference and the recurring themes of how important e-learning is and how more and more is being done via computers. It's not the older family members who use the internet, but the sons and daughters doing the caring ... and an idea I picked up is e-counselling i.e. for CPNs who simply don't have time to get to crisis cases ... at least if e-counselling is set up, the carer can leave messages at any time and the CNP can soon see whether the problem can be resolved via email or whether a counselling session should be set up. Good preventative stuff here and perhaps something our Collaborative can look at ...



**Sushi ... and we ate it!  
Not sure how well I  
liked it, but I ate it!!!**

The other theme that recurred over and over was the importance of making care homes 'homes' rather than institutions and how important it is to make the residents feel part of the community and useful to those around them. A Japanese paper covering person centred care described a woman with dementia so severe that her challenging behaviour drove her daughter away. The staff decided to work together with the daughter to figure out how to give her mother a role in society. She had been a seamstress in her youth, so they gave her a box of buttons, fabric, a packet of needles and some thread. She got so absorbed and quickly picked up her old skills sewing on perfect buttons, that eventually a factory that made jackets sent her their button work to do. She still had dementia, but her challenging behaviour disappeared and she and the daughter were reunited.

I must say I had a real sense that as far as dementia friendly work is concerned, in Scotland and up here in East Sutherland, we're streets ahead of most others around the world ... and we remain one of the few countries in the world to have a dementia strategy that's worth the paper it's written on! And our rural work had so many people coming up and wanting to know more ... it's been an exciting conference and the networking something else!



**Huge stage at the Conference Centre and that's where I gave my papers ... thank goodness for the practice at NHS Annual review at Eden Court last year ...**

There was also time for fun: the conference dinner was held in a restaurant on the 86th floor: there was a interesting menu (not crazy about this Taiwanese food!!) followed by lots of presentations – including the top award of the evening to Babu Varghese from Kerala for his dementia friendly work – and lots of dancing which included Mirna from Lebanon doing fabulous belly dancing while Jim did his Highland fling ... what a night ...



All the pottery ... even the chopsticks ... were made by Wedgewood ... we planned to pinch the chopsticks, but they were too quick for us!



What a menu ...



Taipei 101 ... the second highest building in the world ...we had dinner on the 86th floor ... you felt as if you were in a airplane looking down over the city through the clouds!



## Presentations from the conference:

- The Rocky Road to a Dementia Friendly Community ([presentation](#) and [notes](#))
- Power of the Website Voice ([presentation](#) and [notes](#))
- Churchill Work in India (Poster on the left)

## Two Unexpected Outcomes

Shortly after the ADI Conference, I received an invitation to be a guest speaker at a World Congress on Integrated Care in Singapore in November 2013. The invitation asked me to share:

- 'My personal journey as a carer overcoming the challenges, acceptance, the mind-set change and caring for and working with Andrew to start the Carer's Voice.' This will apparently be targeting carers and service providers who may be providing carer support services; and
- 'The experience of how this ground up programme has garnered the support of the communities and policy makers in starting the dementia friendly community in the Highlands.' They have specifically asked me to focus on the need for policy changes, its challenges and working with the nursing home operators etc. This session will be targeted to policy makers (Ministry of health and other agencies), administrators of hospitals, nursing homes, dementia day care centres etc.

GULP!!

In addition we were delighted to learn in July that our Dementia Friendly Communities initiative has been shortlisted as a finalist for the Scotland Dementia Awards 2013 in the dementia friendly communities category. This award is given for an initiative that:

- Includes people with dementia, their carers, partners and families
- Enables people with dementia to stay empowered
- Maintains the dignity, equality and respect of people with dementia, their carers, partners and families
- Connects people with dementia, their carers, partners and families
- Ensures a personalised approach
- Promotes the understanding of dementia
- Works in partnership with other groups in the public, voluntary or independent sector

All of these points are at the heart of what we have been and will continue to do. So we shall have our fingers crossed on 19 September in Glasgow when the winner is announced!

**What an ending to a fairytale Fellowship: Thank you Winston Churchill Memorial Trust for giving me this extraordinary opportunity not only for Andrew and me to grow and learn, but also the wherewithal to do what I did for dementia!**

## Vision for the future

What is my dream and my vision for the future? First on the list is a cure for dementia, but until this is forthcoming, I'll settle for the only substitute for a cure which is human therapeutic intervention, whether this be in the form of statutory support or simply kindness and understanding by all of society.

India has a population of 1.2 billion spread over a relatively small area. Scotland has 5 million people spread over a huge area, especially in the remote, rural Highlands. But our problem is the same: too few professionals who end up dealing only with crises.

Family, friends and the community in general will see signs of frailty and dementia long before professionals are aware of pending problems. So we need to close the gap between such recognition and crisis. How is my Churchill Fellowship helping to achieve this?

These were my original objectives:

**Objective 1**  
**To develop an early warning system for rural areas in the Scottish Highlands using lay people to recognize early dementia symptoms and early post diagnostic family carer stress.**

That warning system is not yet in place in East Sutherland: we have one CPN to service all of Sutherland, too few doctors and too few other professionals. Right now they can only deal with crisis. So *prevention versus crisis* is still high on the agenda.

However, bearing in mind that true patient centred care is not about putting out fires, but rather about ensuring the fire barriers are there in the first place to prevent those fires from happening, we have an ace up our sleeves: our dementia friendly community with its working Collaborative.

I've come to realise it will be a slow process to get the change we want, but at least the authorities are now listening, including the NHS Highland and Alex Neil, the Scottish Health Cabinet Secretary – see the new [Scottish National Dementia Strategy](#). Indeed with NHS Highland co-operation, I was able to raise this very issue with the Cabinet Secretary at the recent 2013 NHS Highland Annual Review.

So the politicians are also listening. We have 4,000 people with dementia spread over a wide rural area across the Highlands and the number is set to double in the next 20 years. I have been working with local public representatives in the community and local Councillors are keen to serve their constituents in their areas.

Indeed their energy and dedication is being harnessed to shorten the gap between families seeing signs of potential problems and the professionals becoming involved, so that carers can do their job at home effectively with as little stress as possible, while supporting government priorities to reduce costs of acute and residential care.

The Collaborative is also alive and well and living in East Sutherland: moreover it is a network of people who care and who are committed to change for the better. So I have much hope that the groundwork has been laid, especially around the various task groups which will pick up issues and take them forward.

## **Objective 2**

**To link into a system to pass on that information to those who can put proper support in place.**

This objective has been achieved: by working with NHS Highland, Westminster MPs, Scottish MSPs, Local Authority and Alzheimer Scotland, we are committed to take the remote rural dementia friendly community concept across the Highlands. Ultimately I would like to take it across Scotland and then down through the UK. My eventual goal is to link into similar communities across the UK and Europe so that we can all share with and learn from each other.

Being a Trustee on the new £50 million [Life Changes Trust](#) – set up to be a game changer - is also a huge step in the right direction: Trustees were chosen for their innovation, drive and ability to think 'outside of the box'.

I have also linked into work being done at Greenwich University and DFC will be part of a UK virtual research centre (with universities in London, Bath, Bristol, Belfast, Birmingham and Manchester amongst others) addressing '[pain and dementia](#)' research along with other issues.

### **Objective 3**

**To produce training programmes  
for lay staff/family carers.**

This objective has also been achieved locally, nationally and internationally.

I used my experiences in India to produce training programmes for

- Carers (view [presentation](#) and [notes](#))
- [Crossroads Caring staff](#)
- [NES/SSSC Dementia Champions](#)

In the coming months I shall be:

- Teaching a module to 3<sup>rd</sup> year Stirling nursing students in Inverness
- Continuing dementia champion work
- Speaking on *Creativity and Dementia* at the Alzheimer Europe conference in Malta in October 2013
- Addressing the World Congress on Integrated Care in Singapore in November 2013



## Substantiating Documentation

### Papers and presentations

- [Meeting with Cabinet Secretary](#) - Assynt House, Inverness – 19<sup>th</sup> July 2013
- [Words to Stakeholders at Life Changes Trust](#) – 12<sup>th</sup> June 2013
- [Building Bridges for Better Support](#) – Dementia Connections, Glasgow – 3<sup>rd</sup> June 2013 ([presentation notes](#))
- [Power of the Website Voice](#) - Alzheimer's Disease International Conference, Taipei – 20<sup>th</sup> April 2013 ([presentation notes](#))
- [The Rocky Road to a Dementia Friendly Community](#) - Alzheimer's Disease International Conference, Taipei – 19<sup>th</sup> April 2013 ([presentation notes](#))
- [A Carer's Perspective](#) - Big Lottery Carer's Event, Murrayfield, Edinburgh – 26<sup>th</sup> February 2013 ([presentation notes](#))
- [Dementia Dialogue](#) - Inverness/Fort William – 29<sup>th</sup> and 30<sup>th</sup> October 2012
- [NHS Event reading](#) - NHS Annual Event, Eden Court Theatre, Inverness – 5<sup>th</sup> September 2012 ([film](#))
- [What Happens When it Goes Wrong?](#) - NHS Conference: What is Person Centred Health and Care and why do we need it?, Inverness – 24<sup>th</sup> August 2012 ([presentation notes](#))
- [Dementia Programmes for Care Attendants](#) - Helmsdale Community Centre – 23<sup>rd</sup> July 2012

### Resources

- [Alzheimer Scotland Charter of Rights for people with dementia and their carers](#)
- [Scottish National Dementia Strategy](#)

### Websites and blogs

- [Blog posts during trips to India and Taipei](#)
- [A Carer's Voice](#)
- [A Dementia Voice](#)
- [A Care Home Voice](#)
- [A Dementia Friendly Community](#)
- [National Dementia Carers Action Network \(NDCAN\)](#)
- [Life Changes Trust](#)
- [Discussion on pain and dementia](#)