

# James McKillop: dementia ambassador to Japan

Arriving in Tokyo James McKillop had nothing to declare except the right of people to live well with dementia. **Mayumi Hayashi** describes a journey to Japan with a message of hope

**W**hen Glaswegian James McKillop – who has been living with dementia for 15 years – strode towards the arrivals gate with his wife Maureen in Tokyo airport last November he looked up at the customs sign. Had he anything to declare? James smiled. Yes he had – a great deal to declare. He had a positive message of hope and the strong belief in the right to live well with dementia for almost five million people with that condition in Japan.

James' journey to Japan, where he had come to share his design for living well with dementia, had really begun two years previously. Now 74, James had been diagnosed with Alzheimer's at 59. After recovering from the shock of the diagnosis, he rallied – encouraged by staff from Alzheimer Scotland – and realised that he could still lead a fulfilling life. The challenge facing him was to engage with the world around him – and find his voice to express his determination to do so.

Soon, James was talking about his experiences candidly in venues ranging from care homes to conferences. He became a key founder member of the groundbreaking Scottish Dementia Working Group in 2002. The group, led by people with dementia, works towards making life better for people living with dementia through changing society's attitudes and influencing public policy.

Well before his visit to Japan, James had done his homework. He knew that Mount Fuji was three times higher than his beloved Ben Nevis. He knew that 26.7% of its 126.8 million population

were over-65s – with one in seven living with dementia. And he knew that, by 2025, Japan would have a predicted seven million people with the condition.

Two years earlier, he had met Yuji Kawamura, a director for Japan's NHK television, who was in Glasgow visiting the Scottish Dementia Working Group. Kawamura was so impressed he produced a TV programme, "Nothing About Us, Without Us!" which went out across Japan in September 2014. It had a big impact – people with dementia formed their own Japan Dementia Working Group within weeks.

Now, James – accompanied and supported by his wife Maureen – wanted to share his positive outlook with the Japanese. He had been invited to appear at two NHK-hosted "Heart Forums" (informal conferences) in Tokyo and Osaka. The theme on both occasions was "A new dawn – people living with dementia mapping out their destiny." The message from James: to exchange learning and share lived experiences.

## Two cultures, one journey

James was soon sharing his personal journey of 15 years with dementia as well as listening to the responses from two founder members of the Japan Dementia Working Group. He admitted his initial shock on receiving the diagnosis of his Alzheimer's and the long, dark days that followed. He developed his theme by exploring the opportunities for people with dementia in their communities and in society at large. He then

examined how these goals can be achieved and considered the thorny issues of giving and receiving support.

The two founder members of the Japan Dementia Working Group replied, matching James' experiences uncannily. First to speak was Tomofumi Tanno, a 41-year-old diagnosed with Alzheimer's two years previously. Tomofumi provided an almost mirror image of the experiences of James' own journey. Next to speak was Kazuko Fujita, 54, living with dementia for the past eight years. She too mirrored James' journey. The emotion in the audience was almost palpable. For the first time for many of them, they were coming to terms with what people living with dementia have to face.

## Breaking the silence

For James, Tomofumi and Kazuko – along with thousands of others – the weeks and months following a diagnosis of dementia were 'blank' with very little support. Such a diagnosis could have a huge impact on individuals and their families, particularly when the community all around lacked much awareness or understanding of dementia.

So, how does anyone break through the blank period of post-diagnosis despair and isolation?

The key breakthrough was meeting other people living with dementia, Tomofumi said. He added that such encounters gave him hope and purpose. Family members tended to hum and hedge protectively, but a stranger who becomes a

friend will tell it to you straight, though giving it the essential upbeat twist.

How to lead a fulfilling life with dementia? As dementia is not a visible condition, those who live with it have to make their needs known, Tomofumi cautioned. James promoted his "helpcard". It states that he has an illness called dementia and what his needs might be. With this helpcard, he can get the support he needs. Interestingly, Tomofumi came up with a similar idea: every time he shows it on his way to work, numerous strangers are happy to help.

## Influencing public policy

His direct experience of breaking through the initial bleakness led Tomofumi to create "Orange Door" in his hometown Sendai to provide a welcoming meeting place for those living with dementia. Orange Door offers a listening ear, information and guidance – and above all, a sense of hope. Kazuko launched her local group, "Clover", in Tottori, working for – and with – people with younger-onset dementia.

James shared his experiences of the Scottish Dementia Working Group. In another mirror image, Tomofumi and Kazuko are now key members of the Japan Dementia Working Group, championing the need for support during the post-diagnostic 'blank' period. Their success was incorporated in the 2015 New Orange Plan – Japan's national dementia strategy. Both working groups – led by people with dementia – work tirelessly to change society's

attitudes and influence public policy to create a society in which people with dementia and those around them can enjoy a better life.

These direct actions by James, Tomofumi and Kazuko remind us that people with dementia are agents for change and improvement and are cashing in on their lived experience to lead the way towards a better life for their peers, not to mention a more dementia-friendly society, by influencing both the public and dementia policy.

### Now everyone's involved

Both Japan and Scotland have made significant progress in reducing stigma and raising public awareness of dementia. In Japan, the awareness-raising Dementia Friends programme has brought a greater understanding of dementia to 7.1 million Dementia Friends, 5.5% of its total population. The programme is growing rapidly in Scotland.

However, everyone at the Heart Forums agreed that there was still some distance to go before either society became truly dementia friendly. Merely expanding our knowledge and understanding of dementia is not enough, Kazuko said. Public awareness has been raised, but key to moving forward is turning everybody's heightened understanding into helpful actions.

To achieve this, one of the panellists, Kumiko Nagata from the Dementia Care Research & Training Centre in Tokyo, shared two essential elements for turning awareness into actions. First is the realisation that dementia is now everybody's business. In Japan, one in five over-65s will be living with dementia by 2025 and, in Scotland, 76% of respondents in a 2014 survey knew of someone living with dementia.

Secondly, encounters and engagement with people living with dementia are vital, if only to hear at first hand their voices, concerns, wishes and aspirations. Or as James



Top: James McKillop and his wife Maureen in Japan. Above left: Kazuko Fujita. Above right: James chats with Tomofumi Tanno.

puts it – the hopes, dreams and visions that he has. In engaging in this way, opportunities will appear – and supporters can become equal partners. It is important to listen first and not to overdo things, James cautioned, gently banging the 'less-is-more' drum in time with his ideas.

Audiences in Tokyo and Osaka learned that people with dementia wanted to contribute to their communities, enlightening and informing them, offering peer support and promoting policy change. James asked his audiences these two questions:

*If your mother developed dementia, how would you like her to be treated by society?*

*If you yourself develop dementia at some time in the future, how would you like to be treated by society?*

Tomofumi closed his address by revealing that his admiration for James did not stem from his indefatigable work across Scotland and beyond, but simply from 'the man' standing before him. Travelling to Japan had brought James face to face with his peers and to his astonishment they had travelled the same journey,

mirroring exactly his frustrations, fears and hopes.

With Japan's presidency of the forthcoming G7 summit talks in May, the Heart Forum dialogues between Scotland and Japan could be the new dawn of a global conversation to create a dementia-friendly world. That would mean a better life ahead for the 46.5 million people now living with dementia worldwide – and the many millions to follow. ■

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