



SALZBURG
GLOBAL
SEMINAR

Changing Minds: Innovations in Dementia Care and Dementia-Friendly Communities

Wednesday, November 29, 2017

Write! Tweet! Post!

If you're interested in writing either an op-ed style article for our website or the session report, or a personal reflection blog post while you're here this week, please let Salzburg Global Communication Associate Oscar Tollast know or email your submission directly to otollast@salzburgglobal.org.

If you do intend to write for your own organization either while you're here or after the session, please make sure to observe the **Chatham House Rule** (information on which is in your Welcome Pack). If you're in any doubt, do not hesitate to contact Oscar.

We'll be updating our website with summaries from the panels and interviews with our Fellows, all of which you can find on the session page: www.SalzburgGlobal.org/go/587.

You can also join in the conversation on Twitter with the hashtag [#SGSHealth](https://twitter.com/SGSHealth) and see all your fellow Fellows and their organizations on Twitter via the list www.twitter.com/salzburgglobal/lists/SGS-587.

We're updating both our Facebook page www.facebook.com/SalzburgGlobal and our Flickr stream www.flickr.com/SalzburgGlobal with photos from the session during this week and also after the session. (If you require non-watermarked images for your own publication, please let Oscar know.)

We will also be posting photos to Instagram www.instagram.com/SalzburgGlobal. Use the hashtag [#SGSHealth](https://twitter.com/SGSHealth) and we might feature your photos in the newsletter!



@absolutraia: Welcoming Session already exciting! thrilled! #salzburgglobalseminar @SalzburgGlobal



Albert Mulley, Veronique Roger, and John Lotherington set the scene on the first day of the session

Making a Difference in People's Lives

Policy makers, clinicians, carers and service users from around the world have convened at Schloss Leopoldskron, Salzburg, to tackle one of the most serious and growing health challenges for health care.

Around 40 participants from 14 countries met on Tuesday afternoon for the start of the Salzburg Global session, *Changing Minds: Innovations in Dementia Care and Dementia-Friendly Communities*.

This session is part of Salzburg Global's multi-year series *Health and Health Care Innovation in the 21st Century*. It is being held in partnership with The Dartmouth Institute for Health Policy & Clinical Practice, and the Mayo Clinic.

For the next few days, participants will discuss the challenges people living with dementia experience and explore ways in which to better support them and their families.

To set the scene, the six-day program began yesterday with a panel discussion involving session co-chairs Albert Mulley and Veronique Roger.

Roger, director of the Mayo Clinic Center for the Science of Health Care Delivery, described Salzburg Global as a "unique setting" to reflect on "really important critical health issues." She suggested global well-being would require more than the input of the health care system. This view was

echoed by Mulley, managing director for global health care delivery science at The Dartmouth Institute, when he suggested there were other factors to consider.

Mulley said there was a false assumption that the more money spent and the more done on health care interventions would lead to better health and well-being for all. Mulley said social determinants, behavior, and genes provided a far greater contribution.

Taking these views into account, participants began to consider questions they would like answered during this week's program. This included: What do we mean by a dementia-friendly community?

While the meaning and term continue to be debated among participants, several did agree any chance of making progress in this field was dependent on political will and that people living with dementia also had to be involved in the process.

In many countries, there is still much to be done in building awareness around dementia and helping people understand the seriousness of the issue. Cultural differences have to be taken into account when reviewing what actions might be effective in different regions.

These talking points, and more will continue to be analyzed in the days ahead as the session continues.



#SGSHealth @SalzburgGlobal



facebook.com/SalzburgGlobal



instagram.com/SalzburgGlobal

Hot Topic:

“How can we raise further awareness of dementia and improve the lived experience of people with dementia and their families?”

Tomás De La Rosa and Mirva Villa

“[We can do this] by asking the people that live with dementia and their family. Ask them what it is that they would like from a supportive community, and ask them what works but also what doesn’t work... People are very paternalistic and will give what they think we on the ground need, and what we on the ground need is actually sometimes something very much different to what we’re offered.”

Jayne Goodrick

Champion for Dementia Friends, Join Dementia Research, and Health Education England Dementia Workforce Advisory Group, UK. Also supports her husband Christopher Roberts, and her mother, who both have a diagnosis of dementia.

“If we want to create awareness with dementia we’ve got to be able to interact with people who are living with dementia. But aside from that, we have to get to a level where we are able to disseminate the information, right down to the remote villages, I’m from Nigeria, so I’m coming from the background where 75 percent of clinicians don’t diagnose dementia. So we have to get the information right down to the village level. If we don’t do that, I don’t think we are communicating with anybody.”

Babatunde Agbaje

Consultant on health insurance and health care financing to the Oyo State Government and Oyo State Health Insurance Agency, Nigeria

“We cannot continue making activities in order to improve dementia conditions if we don’t include the people who have dementia. On the other hand, I think that the governments must be included in the ideas that we have, in order to develop better conditions for dementia.

Further awareness must include education. Education is one of the most important things that we need to include, but not education just for

professionals or for people who have family with dementia. Education on dementia must be in schools, in the different levels of education that we have, adjusting it to primary and superior education, in order for younger people to know what really is dementia, and that they can be familiar with this condition.”

Erika Salazar

Medical Director at Universidad Latina de Costa Rica, Costa Rica

“I think the most challenging issue as I see it is to go beyond just raising awareness about the public health and societal burden of the disease to the importance of acting upon it, and that responsibility is a shared responsibility. So, if we think about dementia-friendly communities, which is obviously the theme that we’ll be discussing all week, how do you define dementia-friendly community? Whose responsibility is it to create a dementia-friendly community? How do you sustain dementia-friendly communities? How do you really foster the effective sort of synergy between health care systems and dementia-friendly communities? These are really critical pragmatic questions that we have to resolve if we want to improve the well-being of people living with dementia.”

Veronique Roger

Founding Director of the Center for the Science of Health Care Delivery at Mayo Clinic, USA

“There probably needs to be a better social media campaign and better information about dementia in a more holistic way, probably telling more stories about people. I think that works well, and I think sometimes we’re afraid to do that because there’s stigma in lots of communities and people don’t want to talk about it.”

Margaret Mulley

Senior manager at the Dartmouth Institute for Health Policy and Clinical Practice



#FacesOfLeadership

“The simplest answer is that [caregiving] is an issue that affects all of us; it’s not just a narrow niche. This is *us*. We care for our families, and it’s a lot of work. It’s a huge social issue which has been unfortunately deeply overlooked. It’s a big missing piece, and I and my colleagues are excited to work on this because we have the potential to have a huge impact, and we’re bringing in very different talents and backgrounds to this issue of family caregiving than the traditional world of medicine and social work.”

Rajiv Mehta

Project Director and lead investigator at Atlas of Caregiving, USA

Rajiv Mehta explains why he is passionate about working with family caregivers. Atlas of Caregiving is a San Francisco-based non-profit dedicated to studying the hidden activities of family caregivers and discovering ways to help them do their work more easily.

Read more profiles in our series of #FacesOfLeadership online:
[@SalzburgGlobal](https://www.instagram.com/SalzburgGlobal)
www.instagram.com/SalzburgGlobal
www.facebook.com/SalzburgGlobal

Want to join the conversation?
Tweet @SalzburgGlobal using the hashtag #SGShealth



SALZBURG
GLOBAL
SEMINAR

Changing Minds: Innovations in Dementia Care and Dementia-Friendly Communities

Thursday, November 30, 2017

Write! Tweet! Post!

If you're interested in writing either an op-ed style article for our website or the session report, or a personal reflection blog post while you're here this week, please let Salzburg Global Communication Associate Oscar Tollast know or email your submission directly to otollast@salzburgglobal.org.

If you do intend to write for your own organization either while you're here or after the session, please make sure to observe the **Chatham House Rule** (information on which is in your Welcome Pack). If you're in any doubt, do not hesitate to contact Oscar.

We'll be updating our website with summaries from the panels and interviews with our Fellows, all of which you can find on the session page: www.SalzburgGlobal.org/go/587.

You can also join in the conversation on Twitter with the hashtag [#SGSHealth](https://twitter.com/SGSHealth) and see all your fellow Fellows and their organizations on Twitter via the list www.twitter.com/salzburgglobal/lists/SGS-587.

We're updating both our Facebook page www.facebook.com/SalzburgGlobal and our Flickr stream www.flickr.com/SalzburgGlobal with photos from the session during this week and also after the session. (If you require non-watermarked images for your own publication, please let Oscar know.)

We will also be posting photos to Instagram www.instagram.com/SalzburgGlobal. Use the hashtag [#SGSHealth](https://twitter.com/SGSHealth) and we might feature your photos in the newsletter!



@stephclair73 Attending Salzburg Global Seminars Changing Minds: Innovations in Dementia care and Dementia Friendly Communities with @NU_SocialWork



Participants began Wednesday's discussions by reflecting on the stigma surrounding dementia

Reducing Stigma Around Dementia

Stigma is difficult to define, but you know it when you feel it. That was the message which started the second day of the Salzburg Global session, *Changing Minds: Innovations in Dementia Care and Dementia-Friendly Communities*.

The message was delivered by William Hu, assistant professor of neurology at Emory University, as he moderated a discussion which explored how stigma around dementia varies from country to country and the different ways it is being addressed.

Raising awareness of dementia and improving education is not just about providing communities with a greater understanding. It's also about changing the self-perception of those living with dementia.

Chris Roberts, a Dementia Friends Champion and Ambassador for the Alzheimer's Society, said parts of the media had accentuated the stigma around dementia, and that society had reached a point where people failed to realize there was a beginning and a middle to every illness.

Roberts, who has a diagnosis of mixed dementia, vascular damage and Alzheimer's, suggested people should stop using the word "dementia" and start referring to the different conditions by their own names.

Participants considered the different

ways in which the stigma around dementia is reinforced. They reflected on the misuse of language and the patient and carer roles which are often assigned at the point of diagnosis.

One participant said stigma should be challenged from the ground up through education. This point was echoed by another participant who called for a change in curriculum that would provide more opportunities for students to interact with people living with dementia.

Participants shared experiences among themselves throughout the session. The group heard how one man living with dementia in Nigeria was unable to openly share his experience, despite wanting to. The people around him would not let him. The stigma was so strong they feared they would be accused of witchcraft.

To reduce the stigma, a new behavioral change will have to be generated. In Indonesia, the media has played an important role in this regard. A series of multimedia campaigns have increased interest in the subject and has led to requests for more people with dementia to tell their stories.

Advocates and people living with dementia can continue to breakdown barriers by engaging with people from their own countries and communities.



#SGSHealth @SalzburgGlobal



facebook.com/SalzburgGlobal



instagram.com/SalzburgGlobal

DY Suharya - My Work is a Thank You to My Mom

Founder of Alzheimer Indonesia discusses her career path and hopes for the session

Mirva Villa | press@salzburgglobal.org

“Soulful calling.” That’s how DY Suharya describes her work in raising awareness on dementia and working toward improving the quality of life of people with dementia and their caregivers. She is the founder of Alzheimer Indonesia, and the regional director of Alzheimer’s Disease International (ADI) Asia Pacific Region, overseeing 17 countries.

“I have this lifetime commitment to share with people, especially in the Asia Pacific, how you deal with it, how you prevent, reduce your risk, and how you empower, equip and provide support for people with dementia and caregivers, and advocate for person-centered care,” says Suharya. She raises the point while speaking at the Salzburg Global Seminar session, *Changing Minds: Innovations in Dementia Care and Dementia-Friendly Communities*.

The Asia Pacific countries are diverse, but there are some commonalities in terms of challenges with dementia care. One of the biggest challenges is providing support for people with dementia and their caregivers, which Alzheimer’s Disease International is trying to solve through Dementia Care skills training modules, supported by Master Trainers from Alzheimer’s Disease Association Singapore and other ADI members. The program gives local carers tools with which to provide high-quality care.

“If you ask me about challenges, these countries are in a very different place in terms of where they are, and what they need varies. But one thing for sure is they need a pool of talent or a pool of experts or trainers.”

Suharya’s mother has been the inspiration behind her work. She was diagnosed with dementia in 2009, but now Suharya knows that her mother was displaying typical symptoms long before that without anyone realizing it. It caused a lot of tension between Suharya and her mother. “We had our arguments in the past because I did not know what’s going on in her brain.”

It drove her to look for work opportunities abroad, so she wouldn’t have to spend time at home. She ended



DY, pictured above, has more than 20 years of experience in public health, public private partnerships and communication

up working as a journalist, and later as a public health communication consultant for organizations like the World Bank, WHO and UNICEF. She says, “I did everything that would take me away from Indonesia.”

One day, she received a call from her father, informing Suharya of her mother’s diagnosis. In 2012, she decided to come back home after 15 years of living abroad, gathered together her friends and asked them for help in setting up Alzheimer Indonesia, which launched in 2013, on her mother’s birthday. Campaigning to raise awareness of the early symptoms of Alzheimer’s has remained a prominent part of her work.

“Because of my experience, I feel like I can activate people’s highest potential...”

Suharya’s mother passed away six months ago, but her legacy continues in her work. “If not for my mom, I wouldn’t be here. It’s a thank you to her. Because of my experience, I feel like I can activate people’s highest potential, because my potentials were activated through my mom and inspired through the journey of caring for her with the support of my dad and siblings.”

In four years, Alzheimer Indonesia has grown in size and stature. This has included a comic book launch, film festival and choir concert being some of the highlights. There are now support groups in 21 cities in Indonesia, a WhatsApp support group and more than 1,000 volunteers. “Everything I dreamed of four years ago,” remarks Suharya. The newest campaign, called “Love Your Parents,” wants to remind young people to be understanding toward the struggles their parents with dementia might have, to respect their parents and spend quality time with them.

“You cannot raise your voice to a person with dementia. You cannot make the same mistakes that I did. You cannot be angry because you’re accompanying your parents to a bank, and they don’t know where their ATM card is or how to use the telephone.”

Suharya describes herself as a big believer in collaboration and partnerships. As the session progresses, she hopes to see some of the discussion and initial plans held during the session realizing themselves in the future.

She says, “I’m expecting a concrete collaboration that works as a platform to people who share similar goals – whatever they are good at. I like to connect people, and I like to make things happen.”



Salzburg Snapshots

Photos from the first two days of *Changing Minds: Innovations in Dementia Care and Dementia-Friendly Communities*



Supporting People with Dementia From the Point of Diagnosis

“Earlier diagnosis is not optional; it is a human right.” This was one argument put forward during a late morning discussion on the second day of *Changing Minds: Innovations in Dementia Care and Dementia-Friendly Communities*.

Session co-chair Albert Mulley invited participants to share their views on the advantages and disadvantages of earlier diagnosis and the net value it would bring in different contexts.

Participants also considered how families and supporters could be better assisted after diagnosis in planning and shared decision making for the future.

Mulley, managing director for global health care delivery science at The Dartmouth Institute, suggested earlier diagnosis provided the potential to identify populations at risk. One participant, who lives with dementia, said a timely diagnosis did allow him to explain his irregular behavior, but it was more important to him to have the correct diagnosis.

One participant indicated diagnosis as a concept hadn’t been examined enough, arguing, “We say diagnosis, but we mean prognosis. We want to know what happens in the future.”

A timely diagnosis could serve both a social and medical function, participants heard. It enables people to explain how they’re feeling and allows their peers to understand what they’re going through.

If someone receives a timely diagno-

sis, they are able to access the best kind of support: that of their peers. One participant said, “How can you have access to peer support if you don’t know who your peers are in the first place?”

An early diagnosis does not come without its downsides, however, as the group soon learned.

One participant argued moving up the time of diagnosis allows people to be able to control further aspects of life, as well as giving more peace of mind. He added, “On the other hand, earlier diagnosis has the chance of increasing stigma.”

Participants were also reminded to err on the side of caution when scanning for certain diseases before they became medically apparent. One participant warned it was more likely non-progressive diseases would be found.

The downside of an early diagnosis, and the potential of misdiagnosis that comes with it could be the risk of the patient developing mental health conditions, such as anxiety or depression.

If a timely diagnosis is to be made, it is important to ensure the structure of both public and private health systems are renewed.

While highlighting an area of the Pacific Islands that only has access to two dementia specialists, a participant used this as an example to argue how important it was to develop tools that allow timely diagnosis regardless of context and location.



Hot Topic:

“What role can the media play in breaking down the stigma surrounding dementia?”

Tomás De La Rosa

“They can start by reporting the correct news and not just anything they come across. By not reporting on correct news they’re giving people false hopes. They also need to be very conscious of the language they use. Dementia is negative enough without using negative language which is derogatory and not very nice at all. ‘My name is Chris. I live with dementia. I do suffer, my family suffers but I’m not a dementia sufferer. My name is Chris.’ It’s language like that which just brings people down, and as I said is negative enough. They just need to be conscious of a few things and don’t forget that it’s real people that they’re talking about and talking to.”

Christopher Roberts

Dementia Friends Champion and Ambassador for the Alzheimer’s Society, UK

“What they can do is describe the everyday lives of people with dementia, including their family members, carers, and their social networks. I think it’s the best to show a very differentiated picture, and not only interview people with dementia as a single person. I think it’s important that their lives are also embedded in networks and local networks, so people can experience there is still life with dementia and everyday life is going on and continuing, and that support is needed on alternative levels.”

Silke Leicht

Project manager at BAGSO (National Association for Senior Citizens Organizations in Germany), Germany

“The media has a robust role to play by being an agenda setter and molder. The media can only function with the available information at its disposal. So for the media to function, first of all, there has to be a more cerebral approach driven into the efforts to bring about advocacy on dementia through a multi-level system that brings doctors, social workers, lawmakers, politicians, and

administrators together to come up with a global model.

This will help create a synergy and mainstream the particular groupings that drive the process. By doing so, everybody is brought in, and the media, with this multi-level approach, can now seek out available information to give out to the public.

One way to do this is through media advocacy across multimedia outlets, print, electronic, and social media, and it can come up with reports, programs, feature articles, amongst others, that let the world know that dementia is not a death sentence.”

Omini Oden

Currently working in the News Directorate of the Nigeria Television Authority, Nigeria

“From our experience in Belgium, we have run an awareness campaign. It is called, ‘Forget dementia, remember the person.’ That baseline for us is crucial as a starting point to develop other actions aimed at the general public, aimed at the education sector, and aimed at the media. In a nutshell what we see is dementia, apart from a biological pathology, is also in an important way a social construction. We see it as a one sided focus on the later stages of the disease and if we – and especially the media – tends to reinforce that image, we kind of create a self-fulfilling prophecy. If we always say people with dementia have no more capacity, they become isolated, and so on, they’re going to behave like that. I think that’s a tricky and very dangerous thing to do. What we suggest is look at people and what people with dementia can still do, and target your communication on that.”

Olivier Constant

Communications officer at the Flanders Centre of Expertise on Dementia, Belgium

Want to join the conversation?
Tweet @SalzburgGlobal using the hashtag #SGShealth



#FacesOfLeadership

“I started working in psychiatry and found that I enjoyed dealing with the elderly. It was a lot more satisfying in that the little that we could do for the older person was very much appreciated. Then that led me to be studying psychogeriatrics. At that time in Singapore, we recognized that aging was going to be a real issue and that within the elderly community dementia was going to be a major health concern.

As early as 1990, I was involved with the Alzheimer’s Disease Association in Singapore. We did the first project, which was a dementia day care center. It was quite a challenge because even though some of us were trained, we really didn’t know how to run a day center. That was not in our medical education, but we did, and that set the model for future day centers.

What drives me in continuing my work with the elderly and with the Alzheimer’s Disease Association? I think that it’s the lessons I’ve learned from people with dementia and their families. It’s been a tremendous journey in learning how to not only make a diagnosis and do all the medical stuff but in terms of building a relationship with people with dementia and their families. It goes beyond health. It also goes beyond social. It also involves recognizing people as people first who happen to have an illness.”

Ng Li-Ling

Vice-president of the Singapore Alzheimer’s Disease Association, and senior consultant psychiatrist, Singapore



SALZBURG
GLOBAL
SEMINAR

Changing Minds: Innovations in Dementia Care and Dementia-Friendly Communities

Saturday, December 2, 2017

Write! Tweet! Post!

If you're interested in writing either an op-ed style article for our website or the session report, or a personal reflection blog post while you're here this week, please let Salzburg Global Communication Associate Oscar Tollast know or email your submission directly to otollast@salzburgglobal.org.

If you do intend to write for your own organization either while you're here or after the session, please make sure to observe the **Chatham House Rule** (information on which is in your Welcome Pack). If you're in any doubt, do not hesitate to contact Oscar.

We'll be updating our website with summaries from the panels and interviews with our Fellows, all of which you can find on the session page: www.SalzburgGlobal.org/go/587.

You can also join in the conversation on Twitter with the hashtag [#SGSHealth](https://twitter.com/SGSHealth) and see all your fellow Fellows and their organizations on Twitter via the list www.twitter.com/salzburgglobal/lists/SGS-587.

We're updating both our Facebook page www.facebook.com/SalzburgGlobal and our Flickr stream www.flickr.com/SalzburgGlobal with photos from the session during this week and also after the session. (If you require non-watermarked images for your own publication, please let Oscar know.)

We will also be posting photos to Instagram www.instagram.com/SalzburgGlobal. Use the hashtag [#SGSHealth](https://twitter.com/SGSHealth) and we might feature your photos in the newsletter!



@DenleyJu: What a beautiful day in Salzburg @SalzburgGlobal



Left to right - Paul Camic and Sebastian Crutch discuss the relationship between arts and dementia

Mitigating the Impact of Dementia

The role of arts and culture can never be underestimated. The sector acts as a significant source of influence in many areas of society. On the fourth day of *Changing Minds: Innovations in Dementia Care and Dementia-Friendly Communities*, participants considered how the arts could mitigate the impact of dementia, improve communication, and enhance quality of life.

They were guided in their discussions by clinical health psychologist Paul Camic and neuropsychologist Sebastian Crutch. The conversation began with Camic providing an overview of the relationship between arts and dementia in the UK. Participants heard how various artists came together to undertake projects with people with dementia.

Crutch then reflected on the work of William Utermohlen, an American painter. After being diagnosed with dementia, he began painting a series of self-portraits. This enabled artistic reflection and exploration of what he was living with. Arts isn't just a form of intervention, according to Crutch, it's a part of life.

During the panel discussion, participants were introduced to several positive examples of art being used effectively. This included a nod to BBC Radio 3's *Why Music?* residency, which

saw presenters explore choral music and how it can help improve the lives of people with dementia.

Camic showed a clip from the film *Alive Inside - A Story of Music and Memory*, which reinforced this view. It highlighted how one elderly man became reinvigorated when listening to personalized music and found it easier to communicate. He benefited from a charity called Music & Memory.

In response to this clip, one participant asked whether there was potential to produce a similar film concentrating on the work taking place in developing countries.

Another participant said that if the film was shown in her country, members of the public would find it hard to believe what they saw. She suggested the film could be used as a tool for raising further awareness and helping people with dementia.

Arts can play a role in breaking down the stigma surrounding dementia, providing communities further opportunities to engage with people with dementia.

Art programs should ensure people at different stages of dementia are included, one participant argued. One way to fix this could be to embed arts and music in the daily care of people living with dementia.



#SGSHealth @SalzburgGlobal



facebook.com/SalzburgGlobal



instagram.com/SalzburgGlobal

William Hu - “There’s a Lot of Good Work Going on, but Not Enough Credit is Given to the People”

Leading physician scientist reflects on challenges building dementia-friendly initiatives

Mirva Villa | press@salzburgglobal.org

“I hope that we can come up with a concrete action plan to disseminate and share the best practices in dementia-friendly initiatives and communities,” says William Hu, speaking on the third day of *Changing Minds: Innovations in Dementia Care and Dementia*.

Hu, an assistant professor of neurology at Emory University, has his eyes set on the future. Trained as a neurologist and neuroscientist, Hu spends a lot of his time working toward improving the early diagnosis of dementia, and for the past two years has been involved in promoting dementia-friendly communities.

“We have been trying really hard to have an international forum where the lessons from the countries that have been doing dementia-friendly communities for some time can be shared with other countries that are just gearing up to do this.”

When Hu heard about this Salzburg Global session, he saw its potential in contributing to global efforts on improving dementia care.

“I was very excited when I heard that this was happening,” he says. “This really is a continuation of the global effort to talk about what a dementia-friendly community actually means, and how we get there.”

There are great efforts globally toward creating dementia-friendly initiatives and promoting inclusive communities, but several challenges hinder the rate of progress.

Hu says, “One is finding a driver for the initiative. Most of us are doing this as addition to our day jobs, and so finding somebody who will take it on as their primary focus has been a challenge not only felt in the States but also elsewhere.

“Number two, [the] challenge really is the resources and funding. How are you going to get the signage [and] the website hosting? How are you going to pay for travels to learn dementia-friendly practices from elsewhere?”



William Hu, pictured above, has played an active role internationally in promoting dementia-friendly communities (Picture: Salzburg Global Seminar/Katrin Kerschbaumer)

“And finally, a huge challenge is convincing decision-makers that this is something worthwhile doing. The decision-makers usually have a set of goals of their own, and now we’re trying to convince them that having a dementia-friendly community or practice is a positive thing. But how do we compete with other goals such as profit margins, quality measures and the request of shareholders?”

Hu’s day job is closely linked to the dementia cause. His laboratory focuses on using spinal fluid, plasma imaging and neuropsychological measures to provide the most accurate diagnosis as early as possible.

“What that means is that whenever somebody has very mild symptoms of forgetfulness or word-finding difficulties, we can tell very early on whether the Alzheimer’s changes are present in the brain,” says Hu. Part of his research is patient-oriented, which has allowed him to frequently meet people with dementia, with the conversations going beyond the clinical responsibilities of Hu’s work.

“We get to hear a lot about their concerns on the day-to-day level, which is really what got me into dementia advocacy and dementia-friendly communities.”

Speaking further on what kind of actions he hopes to come out of

the session, Hu hopes to see ways of recognizing and promoting the work of ordinary people in dementia care.

“I know firsthand that there’s a lot of good work going on but not enough credit is given to the people who do the good work. A lot of the time it’s the people who have been trained by the professionals, so it’s regular citizens doing the good work. How do we feature these people?”

Hu reflects on the story of two customs officers at Heathrow Airport, who went out of their way to help out a woman confused about where she was traveling. “I’m sure that was not in their job description, but they did it. So how do we reward them, and how do we provide incentives for others to follow their example? That’s what I’d like to get out of this.”

A lot remains to be done for dementia-friendly communities. What motivates Hu to keep working in this field?

“The spirit of people living with dementia and their caregivers. It’s very inspiring to talk to them and hear of their life’s accomplishments and what they still hope to accomplish in spite of the disease. There is a strong human will in illness that comes out, and I’m constantly humbled by interacting with people living with dementia and hearing what insight they have into the disease, but also bigger things in life.”



Building Inclusive Communities

The third day of *Changing Minds: Innovations in Dementia Care and Dementia-Friendly Communities* started with two different panels on dementia-friendly work.

The sentiment echoed throughout the morning was that becoming a dementia-friendly community is an ongoing process. Participants debated what it meant to be dementia-friendly, and whether being dementia-friendly always means being dementia inclusive and dementia capable as well.

Organizations that deal with people who potentially live with dementia should strive for training periodically to make sure staff have the knowledge of best practices when it comes to recognizing the condition, have effective communication skills and are able to refer people with dementia and their caregivers to specialized services.

Integration of dementia inclusivity into existing communities is vital. People with dementia often feel excluded from their community activities, but offering assistance and educating staff on dementia can often lead to sustainable, positive change.

One panelist argued a person with dementia has the right to continue living their life as usual. Instead of creating designated spaces for people with dementia, existing institutions, such as museums and public transport, should become dementia inclusive.

Reducing stigma was once again brought forward as a method to make communities more dementia-friendly. In countries like Nigeria, where a word for dementia doesn't exist, providing more information on the condition through the work of the ambassadors

has proved to be a valuable way to help the local communities. One participant noted that southern states in the United States often had similar challenges to countries like Nigeria, regarding lack of knowledge and their attitudes toward dementia. Promoting understanding of the condition would help ensure high-quality care.

The possibility of creating a global symbol for dementia-friendly initiatives was discussed. While the benefit of unified symbols was seen, a participant said the focus should be on breaking down the unique problems of each sector and the challenges posed by different public institutions.

Another participant remarked that labels are not important. Ensuring that the community steps in to help is the key, and people don't shy away when they see a confused person.

Building a movement around dementia care, and activating existing communities is a positive way of moving forward. A participant from the UK noted volunteers want to become increasingly involved in the dementia cause.

Fellows from Indonesia shared an example of the campaign held by ALZI, where people wearing purple campaign shirts take photos of themselves at famous landmarks. This encouraged more and more people to get involved, causing a snowball effect.

Collaboration, identifying the champions and reaching out to them was seen as the key to building a successful campaign. Several participants said there was a need to keep the individual with dementia in mind – whether it was to plan movements, evaluate services or build inclusive communities.

Salzburg Snapshots

Photos from the fourth day of *Changing Minds: Innovations in Dementia Care and Dementia-Friendly Communities*



Hot Topic: “What are the essential characteristics of a dementia-friendly community, and how are they best realized among under-served populations?”

Tomás De La Rosa

“An essential characteristic of a dementia-friendly community is, firstly and most importantly, people being aware if there are people living with dementia among them. This is enough for the first stage of establishing a dementia-friendly community.

In terms of under-served populations like Indonesia, because we are in the low-middle income countries, I think the best thing is to work with the government. We are activating the government structures from the municipality, from the macro community until the micro-community; for instance, from the city to the town, and then to the village, they have these communities, so we activate them.”

Amalia Fonk-Utomo

*Chairperson for Alzheimer Indonesia
Nederland Foundation*

“Inclusiveness of people who have dementia and the people who support and provide care, as well as a structured supporting system supported by governments, and using the public resources. Just encouraging the private community, or the people of a community is not enough, government support is really important.

For these to realize among under-served populations, government support is again very important, as well as leadership, to capture the attention of a population in a country or community and show them they are responsible for their municipal area.

For this integration to happen, grassroots and top-down approaches are both very important. If there is a grassroots approach and then they raise the problem to the government, but the government doesn't want to do that, nothing happens... the government cannot capture everything without the support given by the grassroots approach.”

Ryoma Kayano

Professional staff member of the WHO Center for Health Development, Japan

“Dementia-friendly communities should focus on projects directed to human rights in order to get the best benefits and have legal support for their initiatives. [These projects could include] providing caregiver support, looking into early detection for cognitive impairment, planning awareness campaigns on risks that could lead to developing cognitive impairments, working on sensitizing new generations, and integrating different areas of the community including private and public institutions.”

Norbel Roman Garita

President of the Alzheimer's Association of Costa Rica

“The best solution would be to use the human rights lens perspective to find an answer to the question. Concerning under-served populations, human rights are especially interesting. If we don't give a voice to the voiceless, and we don't protect those who are unprotected or whose rights are violated, we will never manage to realize their needs...

We should not forget that the realization of the right to health is not a separate right, it cannot stand alone. We should also think about other approaches about the right to labor for example, to employment, about the right to social protection, to living in housing facilities with dignity, [and] the right to vote. We should not condemn these people to a civil death, as we call it in legal language.”

Katerina Nomidou

Member of the pool of experts of the European Council's Consumers, Health and Food Executive Agency, Greece



#FacesOfLeadership

“I'm very interested in the dementia friendly communities, rather than medical issues or caring issues. The reason is, I used to work as a TV program director eight years ago, and at that time I covered people with dementia and their families. I noticed that in some communities, they are living very well with dementia, but in other communities, they are very unhappy, and [people] have to move to care facilities or psychiatric hospitals, even if they didn't want to go there. I think that dementia is not only a medical issue or a care issue, it's a community or social issue.”

Takehito Tokuda

Board member of the Dementia Friendly Club (DFC) and a visiting researcher at Tsukuba University and the International University of Japan, Japan

Takehito Tokuda explains what motivates his work. The DFC is a non-profit organization which promotes dementia-friendly communities all over Japan. As of 2017, it has 21 branches and more than 700 members.

Read more profiles in our series of #FacesOfLeadership online:

[@SalzburgGlobal](#)

www.instagram.com/SalzburgGlobal

www.facebook.com/SalzburgGlobal

Want to join the conversation?
Tweet @SalzburgGlobal using the hashtag #SGShealth



SALZBURG
GLOBAL
SEMINAR

Changing Minds: Innovations in Dementia Care and Dementia-Friendly Communities

Monday, December 4, 2017

Write! Tweet! Post!

If you're interested in writing either an op-ed style article for our website or the session report, or a personal reflection blog post, please let Salzburg Global Communication Associate Oscar Tollast know or email your submission directly to otollast@salzburgglobal.org.

If you do intend to write for your own organization, please make sure to observe the **Chatham House Rule** (information on which is in your Welcome Pack). If you're in any doubt, do not hesitate to contact Oscar.

We have been updating our website with summaries from the panels and interviews with our Fellows, all of which you can find on the session page: www.SalzburgGlobal.org/go/587.

You can also join in the conversation on Twitter with the hashtag [#SGSHealth](https://twitter.com/SGSHealth) and see all your fellow Fellows and their organizations on Twitter via the list www.twitter.com/salzburgglobal/lists/SGS-587.

We've updated both our Facebook page www.facebook.com/SalzburgGlobal and our Flickr stream www.flickr.com/SalzburgGlobal with photos from the session. (If you require non-watermarked images for your own publication, please let Oscar know.)

We have also posted photos to Instagram www.instagram.com/SalzburgGlobal. If sharing memories of your time at Schloss Leopoldskron on social media, please use the hashtag [#SGSHealth](https://twitter.com/SGSHealth).



@stephclair73: Thank you to Claudette and Chris for giving us the very important perspective of people living with dementia @mason4233 @NU_SocialWork @SalzburgGlobal #SGSHealth



Fellows of *Changing Minds: Innovations in Dementia Care and Dementia Friendly Communities*

Salzburg Statement to be Produced on Dementia-Friendly Communities

Participants from 14 countries have agreed to develop a Salzburg Statement to use as a framework when approaching governments and organizations on dementia care issues.

The decision was made on the fifth day of the Salzburg Global session, *Changing Minds: Innovations in Dementia Care and Dementia-Friendly Communities*, which is part of the multi-year series *Health and Health Care Innovation in the 21st Century*.

Leading up to this, 40 participants had spent four and a half days discussing the stigma surrounding dementia and what a dementia-friendly community entails.

They also took part in plenary sessions addressing various aspects of life with dementia, including how innovations in dementia care can reduce the stigma surrounding the condition and make a difference in people's lives. Participants also reflected on the benefits of a timely diagnosis and the role of arts in mitigating the impact of dementia.

On the fifth day of the session, participants presented six sets of recommendations addressing different elements that make up dementia-friendly communities and how to apply them in a global context. After their presentations, participants agreed a Salzburg Statement would be the prime

vehicle to bring together these proposals and take decisive action moving forward.

The first group, which addressed community empowerment, produced a strategy oriented toward giving self-confidence to people with dementia and the people around them through education and tools, active engagement in professional care, and knowledge of their legal rights and how to access them.

Through this approach, they hope to help create more safe spaces for people with dementia through professional acceptance of family leadership, community networking and social conversation platforms, and the creation of a general environment of inclusiveness and dignity.

The second group looked into research priorities within dementia-friendly communities. These were established based on the needs of those living with dementia and their carers. The first of these priorities focused on issues such as the role communities can play in screening and addressing people with dementia and caregivers at the time of diagnosis and providing initial educational and care plans.

Continues inside.



#SGSHealth @SalzburgGlobal



facebook.com/SalzburgGlobal



instagram.com/SalzburgGlobal

Amy Little - The Biggest Challenge is Raising Awareness that Dementia is a Medical Condition

Executive lead of Global Alzheimer's and Dementia Action Alliance speaks to Salzburg Global

Oscar Tollast | otollast@salzburgglobal.org

When Amy Little decided to attend the Salzburg Global session, *Changing Minds: Innovation in Dementia Care and Dementia-Friendly Communities*, she did so for one reason: "It's a global session with people from all aspects of dementia and many different parts of the world, so that fits in perfectly with the work that I do..." she says, speaking in Schloss Leopoldskron's Robison Gallery.

Little leads the Alzheimer Society's international work and is the executive lead of the Global Alzheimer's and Dementia Action Alliance (GADAA). The latter of the two is a network of international civil society organizations looking to champion global action on dementia. Its steering committee includes the Alzheimer's Society, Alzheimer's Disease International, Age International and Dementia Alliance International.

"The premise of the network is that after the G8 global action on dementia that was initiated in 2013, there was a realization that we needed to mainstream dementia, and we needed the non-dementia world to realize the global problem and how they could actually be part of the solution."

The Alliance acts as a bridge connecting international non-governmental organizations (INGOs). Little says, "[They] could be from the disability sector, human rights, older people and aging, women's organizations, international development. [It's] looking at that spectrum of INGOs to help them realize that dementia is a global problem and that actually it can be part of their agenda as well."

GADAA works with these organizations to raise awareness around dementia and support advocacy efforts. Further down the line, the network is looking at ways it can disseminate tools and best practices to interested parties.

In her role at the Alzheimer's Society, Little helps share the UK's experience of dementia and forges partnerships with other countries "to take global action



Amy Little at the Salzburg Global session, *Changing Minds: Innovation in Dementia Care and Dementia-Friendly Communities*

on dementia forward." The Alzheimer Society supports the UK Department of Health as a delivery partner. Little says, "One example is the Global Dementia Friends Network. We are working with 27 countries who have or are in the process of developing Dementia Friends. We want that number to go beyond 27 obviously. We have shared our program and resources so other countries can adapt those."

Various countries are at different stages of development when approaching dementia, which Little admits is a challenge. She says, "Sometimes I describe it as the elephant in the room. I come and talk about dementia, and at first, you get a blank face: 'Why are you talking about dementia?' There is still that stigma and assumption that dementia is a natural part of the aging process rather than a medical condition. The biggest challenge that we have is that awareness that dementia is a medical condition."

Little says this challenge applies to every country, including those seen to be leading on dementia. "I have spoken to people from ministries of health who

claim, 'We don't have this problem in our country.' It is a big, big challenge we have got to meet."

According to the World Health Organization, the number of new cases of dementia each year worldwide is nearly 7.7 million, suggesting one new case every four seconds. Last year, the Office for National Statistics revealed dementia was the leading cause of death in England and Wales in 2015. While data such as this highlights the impact of dementia, Little asks, "Why in that case don't more people know about it?"

Speaking on the fifth day of the session, Little says she's found the experience "very enriching" and is grateful for the time and space to talk more in-depth with her fellow participants. "It has gone too quickly," she laughs. "Five days feels like a long time, but it has actually gone very, very quickly. It feels like there is so much more we can do and should be doing. It seems to me the purpose of the Salzburg sessions – or one of the purposes – is to foster those relationships that then more happens after as a result."



Continued from front page.

The second priority was community-based care and services, which includes focusing on support for challenges people with dementia may face, caregiver support, and supportive social structures. The last priority suggested looking at alternatives to institutionalization for people with disabling dementia, how to manage complications, and how to make end-of-life care more humane.

The third group designed a roadmap providing guidance for effective dementia education and training programs. Its elements included target groups; skills, knowledge, and attitudes at different levels; consideration of needs; learning methods; insurance of accessibility; and culturally appropriate systems. Through it, the group hopes policymakers, educators, local communities, researchers, individuals, and institutions, would be able to design more effective dementia-friendly communities.

Inspired by their meetings in Schloss Leopoldskron's Max Reinhardt Library, the fourth group proposed the creation of an information library on dementia. It would be publicly accessible and professionally curated in consultation with dementia-friendly initiatives. The library would also introduce Wiki-style entries for dementia-friendly projects and organizations, which would contain work details such as their mission, goals and progress, contact details, location, and crowdfunding links.

The fifth group focused on dementia-

friendly innovations in medical care. Their project looked into how communities and individuals can have a role in health facilitation for front-line staff, such as medical carers, to learn the needs and wants of people with dementia. Through this, they'd be able to provide care navigation, resources to a wider team in more complex issues, and prepare for life-course stages.

The final group explored the steps to build on to further awareness in dementia-friendly communities. This "Global Communication Network on Dementia" would help transform ideas into actions across various countries. This group suggested the moment is prime for introducing the project, as there is a "worldwide need for an open source network." Among other actions, this would allow people to exchange best practices for care and build awareness of how communities can be dementia-friendly. The network's core belief is, "Together we can build bridges, relationships to broaden horizons and inspire each other to improve the lives of people with dementia and carers."

Veronique Roger, a representative from session partner Mayo Clinic, said the outcomes from this session would allow the different parts of dementia care to be more synergistic. To finish she added, "We have an opportunity to go after the goals we have set for ourselves [...] It will never be enough, but if we start now we will have more than what we started with."

Salzburg Snapshots

More photos from the Salzburg Global session, *Changing Minds: Innovations in Dementia Care and Dementia-Friendly Communities*

