International Examples of Community Action for Mental Health – A case study approach.

In alignment with the report for Community Action on Dementia -

‘Living With Dementia in today’s community: Brent.’

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- Case study #1 - Kerala Dementia Friendly Initiative

Kerala has a unique problem, it is the Indian state with the largest elderly population and the slowest population growth equating to a lack of young and able people to support older people. In response to this risk this poses to those with dementia, Kerala’s government has created a model of health care through various pioneering initiatives, and is consequently now recognised as the model of dementia care for all other Indian states and south Asian countries.

Interesting features: The crucial feature which makes this project unique is the government’s attitude towards dementia as a separate issue to general geriatric care, whereby the associated issues can only be addressed through a specific and stand-alone health strategy. To do this, the government has made dementia a social welfare and public health priority and through the establishment of a collaborative care model is being actioned by Alzheimer’s and Related Disorders Society of India (ARDSI), the Department of Social Justice and the Kerala Social Security Mission. The collaborative nature of the model is regarded by some to be the defining feature of the success of establishing Kerala as a dementia-friendly community.

To stimulate comprehensive community awareness of dementia the government has launched multiple ambitious initiatives simultaneously, which range from equipping all health and social care personnel with the necessary care skills to launching vast numbers of volunteer groups at the gram panchayat level (small town/village self-government) whose role is to take care of those showing symptoms of dementia. To illustrate the vast scale of this initiative, there is in excess of 265,000 gram panchayats in India, each of whom has been tasked to train at least 100 volunteers with support from ARDSI. The model available for gram panchayats to learn from is the ‘We Care Volunteer Corps’ which is run by the Kerala Social Security Mission, whose objective in Kerala alone is to create a corp of 100,000 volunteers in Kerala alone to act as a social security network and provide primary care for the 200,000 elderly people in Kerala.

The five components of this dementia care initiative also include equipping medical colleges with memory clinics for early diagnosis, standardising procedures in care home and protocols for treatment and support, and lastly to maintain a telephone based Helpline for information and support: thereby creating a 360 degree strategy. As this is a government initiative, the components are funded by budgetary allocation set aside for the welfare of marginalised groups and shall continue to be evaluated year on year to ensure the correct amount of budget can be allocated, and ensure the initiatives’ success.

Where/who: Kerala, a Southern Indian state where the government has generated a collaborative approach to dementia care initiatives, through the Department of Social Justice, the Kerala Social Security Mission and the national Alzheimer’s society - ARDSI.

Benefits: The benefits of this government-led approach are multi-faceted as it targets not only all types of people within society, but the various structures which shape society. Ultimately, those with dementia should experience a better quality of life and therefore be the main beneficiary of the
initiative, however by growing public understanding and aligning this with a top-down service response, the initiatives will build on momentum to positively change social perception of mental health in society. This will benefit those who are indirectly affected by dementia and related conditions, such as family members and friends, by providing them with emotional and practical support. The project is highly ambitious in its scale and acts as a prototype for dementia care in less economically developed countries, making the potential benefits of this project considerable.

A memory walk held as part of an awareness programme organised jointly by Alzheimer's and Related Diseases Society of India, the Social Justice Department and Kerala Social Security Mission

- Case study # 2 - Clippers n’ Curls for the Heart
Clippers and Curls for the Heart is a collaborative initiative dedicated to preventing heart disease and stroke in the African American population, by training barbers and beauticians to deliver heart health messages to their clients and refer them to clinics if appropriate.

**Most interesting features:** Heart attack and stroke is recognised to be prevalent for those of African American descent and this project is taking advantage of a naturally occurring setting whereby social bonds exist between people from outside of one’s immediate network. Barber shops and beauticians play an important role in these communities as a safe haven whereby clients can confide in someone, build relationships and ultimately have a trust level enabling confidential hopes, dreams and anxieties to be shared. This collaboration between barbers and healthcare professionals can therefore be seen as an organic process, a partnership which already has a place within society. It is important to note that this concept is not new or revolutionary, the historical notion that barbers were regarded as healthcare experts and trusted professionals within society (as far back as Egyptian times) is a main reason for this projects conception and helps contribute to the projects almost seamless introduction into society, driving the projects success.

The project informs barbers and beauticians about stroke and heart attack and equips them through training to recognise the symptoms of the condition (such as light headedness). They are also trained to screen blood pressure, educate individuals and if necessary, signpost clients to the services available to help them with their health.

**Where and who:** Through creative and innovative programming with barbers, beauticians and shop owners using established shops and salons in the Twin Cities Metropolitan area, Minneapolis and St. Paul.

**Who Benefits:** The main beneficiaries of this innovative collaboration are those who do not recognise that they have any problems with their health, yet are receptive to the help of others. Instead of ignoring symptoms due to a lack of awareness, these people have the opportunity to seek help and obtain healthcare advice thereby potentially avoiding a fatal situation.

Barbers and beauticians can also be seen to benefit from the collaboration and they are using their place within society to help others; they are accessible and trusted individuals who have the opportunity to play a vital role within their client’s life beyond their job as a barber. Disseminating their knowledge about healthcare needs and diagnosis to the public will help to encourage community awareness and understanding within the African American population, allowing them to support each other to live better and not be embarrassed to seek healthcare assistance.
Clippers n’ Curls for the Heart

preventing heart disease & stroke

Example barber shop with medical equipment
Focus on: The Physical Environment

- Case study # 3 – Together for a dementia friendly Bruges!

Together for a dementia-friendly Bruges! is an all-inclusive community based long-term awareness programme to fight stigmatisation associated with the dementia.

Interesting features: This community based push towards societal inclusion of those with dementia is based upon various projects simultaneously aiming to raise awareness and make public spaces and facilities accessible for those with the condition.

Adopting the physical environment is key to encouraging inclusion as this will encourage greater understanding and encourage a positive change in attitudes. To achieve this Together for a dementia friendly Bruges! has created various projects which address specific challenges those with dementia face: outdoor space for those with the condition to rest and relax when out and about; a choir only for those with dementia and their carers as music is believed to help stir lost memories; a local police database to find residents prone to wondering and speed up the search process by efficiently collating key information such as their last location, their prior work address and what they were wearing; dementia councillors to provide specialist support and therapy to those with the condition and their families independently of one another; and lastly, standardised training for shop owners who present ‘red handkerchief’ signs on their shop fronts to visually signal that they are ‘ready to help’, making the shops physical places which are considered dementia safe.

Championed in Bruges is the approach that creation of a dementia friendly community is an ongoing improvement process to reduce the hurdles that those with dementia experience when out and about. This is illustrated by various outlets simultaneously acting to increase awareness and change perceptions and should not be given time frames with which to be considered dementia-friendly; improving inclusion is seemingly regarded an organic process and should be allowed to entrench itself in society naturally.

Where and who: Bruges in Belgium, a tourist city where 2000 people live with dementia, two-thirds of whom still live in community.

Who benefits: Primarily, these projects are there to help those with dementia live better and remain a valued part of society. Importantly however, caregivers are also specially targeted by this approach, for example by sharing responsibility of a wondering person between the community. The carers worry and stress can be relieved as they know that the person with dementia can find respite in safe havens and that members of the community are going to treat the person with dementia with respect. This approach is by the community for the community, it is hoped that all those who are aware of dementia will benefit by increasing their understanding of the condition and learn how to change their behaviour to be more accommodating and inclusive.
The red hankie displayed in a shop signifying dementia friendly status
Focus on: Community-based innovation services through local action

- Case study # 4 - TimeSlips Creative Storytelling

A programme aimed to transform dementia care through creative improvisation and poetry, engagement methods which are not typically impeded by dementia.

Interesting features: This form of creative engagement enables individuals or organisations to become specifically skilled in engaging with those who experience memory loss. High skill ability is recognised by certification in the programme and ensures that those practising creative engagement do so in an ethical manner.

Improvisation, imagination, art and poetry are the main chosen creative outlets to encourage engagement, as neither skill is inhibited by dementia. By engaging in activities which specifically target areas of the brain not affected by dementia, people with dementia can express themselves freely and connect with those around them on a level unconstrained by the condition and cultural norms. Quite simply, those with dementia are “replacing the pressure to remember with the freedom to imagine”. The movement towards imagination and improvisation has been awarded for Innovations in Alzheimer’s Caregiving, and the MetLife Leadership Award through the National Centre for Creative Aging.

Where and who: Founded in 1996 by Anne Basting, the company stemmed from a play she wrote about reminiscence-based techniques and imagination called ‘TimeSlips’, and shared it with the community. Since then it has grown into an independent non-profit, curated numerous plays and art exhibitions and trained over 2,000 TimeSlips Facilitators from across the world.

Who benefits: It could be argued that the main beneficiary of this dementia care programme is those with dementia: the programme allows them to engage with those around them, helping to build confidence and empower those with dementia to express themselves creatively without being constrained by their memory loss. This encourages an equal relationship between the carer and the person being cared for as both are engaging in a medium of communication which is not first nature, both putting in effort to be understood by the other as opposed to assuming someone to understand you. Those providing the care also benefit heavily from this programme, through giving them an alternative outlet by which to engage and communicate with the person with dementia and facilitating a deeper understanding of the person they care for. The relationship between the caregiver and the person with dementia could therefore be argued to be the main beneficiary of this programme.
TimeSlips in full swing; example art work by a class attendee

He's got long legs. Oh boy!
He sure is jumping.
He is into the music

— By: Luther Manor Read more »
Focus on: Transport

- Case study # 5 - Fake Bus Stops

_A system specifically designed to calm the anxiety typically expressed by those with dementia in a care home setting, whereby those with dementia are empowered to act on their desire to be elsewhere and leave the home, as the system ensures they are safety returned_

**Interesting features:** This initiative recognises wondering and wanting to be elsewhere as a behavioural trait which is common to dementia within the care home environment and aims to calm the anxiety and consequent negative emotions felt when the person is not allowed to leave. This is therefore a user-led approach to behavioural management, whereby the needs of those with dementia are prioritised and services are designed in response to behaviours common to condition.

The creation of these fake bus stops is the outcome of collaboration between public transportation departments and local care associations to create exact replicas of standard bus stops. The system allows the person with dementia to sit at the fake bus stop until they want to return to the care home, as no bus will visit the stop so there is no danger of the person wondering. The only goal of this initiative, as outlined by the International Association of Chiefs of Police, is to diffuse the anxiety and panic often exhibited by those with dementia due to wanting to be elsewhere. The person with dementia is therefore given autonomy to express their emotions and given the choice of when to respond to the carer and be redirected to the care home.

**Where and who:** Originally piloted and carried out in Germany and due to its success, now also features in other EU countries. The system was designed and implemented through local public transport partnership with local care associations.

**Who benefits:** The benefits of this programme are largely limited to those with dementia. They maintain the control to act on their emotions, and therefore retain a sense of agency and confidence. This encourages them to control their emotions without help from others, lessening the load and stress on the care worker who also consequently also benefits from this care system. This sense of self-control felt by the person with dementia is heightened by the choice they have to return from the bus stop to the care home when they want and with whom they want. This partnership of local services therefore empowers those with dementia to remain retain some independence.
An example of a fake bus-stop in Germany
Focus on: Faith

- Case study # 6 - Dementia Friendly Gurudwaras Project, Bradford

An education project run in a Gurudwara (Sikh temple) by Sikh healthcare professionals aiming to raise awareness and reduce the stigma associated with dementia.

Interesting features: The gurudwara is a hub of spiritual worship, arts, language and learning of traditional scriptures. The Ramgharia Gurudwara in Bradford has been recognised nationally and internationally by Alzheimer’s Society Dementia Friendly Awards as a pioneering project in the creation of dementia friendly community within a context whereby dementia is highly stigmatised. Due to the projects success, the initiative has created a step-by-step ‘Toolkit’ of help and advice for other gurudwaras to use, and as such is an acting example for those who want to shift perceptions towards positive understanding and inclusion of dementia in their communities.

To create awareness and a sense of belonging for those with dementia within the temple, several initiatives have been undertaken simultaneously: altering the physical environment; training key sevadars (volunteers) to learn how to manage dementia associated behaviours; creating a community of 50 Dementia Friends from the congregation; physical and virtual information portals on dementia e.g. leaflets and podcasts; and lastly, a monthly memory café where people with dementia and their carers can meet and support one another.

Where and who: the Bradford-based initiative was launched by husband and wife, Dr. Singh and Dr. Grewal. Both are in medical training, with Dr. Singh training as a GP and rehabilitation medicine specialist, and Dr. Grewal as a palliative care consultant. The couple have set up this initiative in their local temple, named Ramgarhia Gurudwara.

Who benefits: The gurudwara is a place where those with dementia can benefit from the spiritual inclusion and community bonding to help them live well with their dementia, within a community whom previously marginalised those with dementia. The rest of the congregation benefits largely from increased awareness and in their ability to help those with dementia. Similarly from a community perspective, the congregation can become advocates for the importance of spiritual and religious settings to provide help, and in doing so encourage similar gurudwaras to become dementia friendly.

The Toolkit is a comprehensive and easily digestible action plan outlining start-up advice. It emphasises the importance of engaging with people with dementia through various methods, each of which addresses challenges those with dementia face: informal face-to-face discussions to overcome barriers to speaking openly; environmental changes such as signs and pictographs to help overcome confusion in navigation; physical information portals in multi-dialects to reach and disseminate information to those who feel stigmatised; lectures and workshops from healthcare professionals to educate individuals and create connections to local professionals; and lastly, weekly classes to educate children to grow their awareness and reduce stigma from the bottom-up. The Toolkit is freely available as is advice from the gurudwara, which now acts as an umbrella organisation to help other communities succeed.
Forming a Dementia Friendly Gurudwara Project; Seven Stage Model

1. Recognize the problem
2. Deciding to act
3. Understanding the needs of the community
4. Approaching the management committee
5. Implementing Action Plan
6. Networking
7. Reassessing the situation

The Seven Step Model to developing a Dementia Friendly Gurudwara Project, from The Toolkit available for download.
Focus on: Caregiver Support

- Case study # 7 - HEKL : The Missing Persons project

A network based approach to locate and return home missing persons through police and community collaboration

Interesting features: Initiated seven years ago, the healthcare sector has motivated the police force within five neighbouring areas to join together to form a united police force to search for a missing person, a typical behavioural symptom of Dementia. This initiative has been awarded the 2012 European Foundation Initiative ‘Living Well with Dementia in the Community’

Presently the 195 local police forces in Belgium operate separately under a federal force, however this approach reverses this and strives for collaboration between local forces to increase the chances locating and returning a wondering person. The protocol signifies that all partners involved must support the professional police communication to be actively involved in providing fast access to documentation on the missing person, including information about the ‘last point seen’ and personal details. Within the area of HEKLA, the return time is short if identified quickly; a search can last up to an average of two hours.

Where and who: This project has been rolled out in Belgium and was initiated in 2006 by five local authority areas - Hove, Edgem, Kontich, Lint and Aartselaar. Due to its success, a further 75 local police forces have adopted the approach.

Who benefits: The beneficiaries of this approach are twofold: first, those with dementia benefit as not only will they be returned home quicker, but the efficient processes in place can help make the experience of getting lost less stressful. Simultaneously, the caregiver benefits as the collaboration with the police and community bodies allows the search to spread wider more quickly as a network of people become instantly informed about the missing person, providing greater peace of mind to the caregiver. This project also seeks to normalise wondering behaviour common to dementia, and acts to defy stigma and encourages the public to become more aware of behavioural symptoms of dementia and provide support for each other.
Case study # 8 - Dementia Aware Donegal

This programme has successfully created and maintained a dementia friendly community through five key project components to spread awareness and understanding of dementia; ultimately creating community support to the 2,000 families living in Donegal with the condition.

Interesting features: Each of the projects aims to not only stimulate societal change but actively maintain Donegal’s status as dementia-friendly community (DFC). The components aim to infiltrate understanding through all corners of society: ‘Be a sport for dementia’ is an initiative to encourage and support those with dementia to continue with their local sport club involvement; ‘Ordinary Man, Extraordinary Memories’ uses theatrical plays to enhance community understanding and awareness and is actively reaching out to primary schools; ‘You’ve got a friend in me’ aims to establish a network of Dementia Champions who will specially train teams of dementia friends; ‘Hearth and Home’ wants to stimulate support for people living with dementia within the community; and lastly, ‘Faith, hope and charity’ aims to support the clergy to provide pastoral care for their congregations through recognition of best practise.

The rationale behind the 5 pronged approach is embedded within WHO’s principles of Age Friendly Cities, which have been developed into constructs encouraging Dementia Friendly Community’s to grow. Each of the above projects has been specifically designed to incorporate a variety of these constructs whilst simultaneously including new emerging principles necessary to support those with dementia in the community. The major constructs include: enhancing public awareness and information access, changing to the physical environment, considering the opinions of people with dementia within planning processes, changing access to transport and public services to suit their needs, and lastly, highlighting the importance of community based innovation through local action.

Where and who: The 5 strands of this project are based in Donegal, Ireland and are being actioned by a wide net of people for each project.

Who benefits: The beneficiaries of this programme are inclusive of those within society, not only those who are specifically involved in theatre or sports clubs, but all who interact with society. This all-encompassing reach is due to the multilevel approach which has been adopted by the 5 differing projects (such as the bottom-up effect through sports and theatre to the top-down alterations within business and public services) and aims to create society change across several key areas simultaneously. The overall effect from the projects when combined should not only help those with dementia and their caregivers and family, but increase awareness and support for those with dementia by all members of society due to the changes occurring at various levels of societal structure.
The winners of the creative writing competition

Alzheimer’s. We all forget.

3 or 4 new families will be affected by Alzheimer’s in Donegal this week and next week and the week after that...

An Evening of Information and Ideas
Room 1401, Letterkenny Institute of Technology
Wed. 12th Nov. - 7.30pm - 9.30pm

Come along and find out about the illness and what you or your group/organisation can do to help family members, friends or neighbours living with the illness.

For more information contact:
Alastair on 087 641 7576 or alastair.mckinney@alzheimer.ie
or Diane on 087 2770103 or diane.donnelly@hse.ie
Focus on: Public awareness and access to information

- **Case study #9 - Stoke Damereel Community College**

*Stoke Damereel are exploring ways in which to bring education about dementia into the school environment, with aspects intertwined across the whole curriculum.*

**Most interesting features:** Stoke Damereel is a Dementia Pioneer School, a school which is investigating and testing various methods to bring education about dementia into the British curriculum. This aims to break down stigma and stereotypes and instead instil understanding of the condition in the young of society, thereby encouraging a dementia friendly community from the bottom-up.

The project has worked to incorporate dementia education across eleven subjects: Health and social care, Science, Sport, ICT, Religious studies, English, Media/Drama, Maths, Languages, Hospitality and Work skills. For instance during science classes, pupils are exposed to the biological side of dementia and are taught how different diets and food plans can contribute towards the development of the condition. Similarly in sport class, students play games with residents of a local care home where dementia and memory loss does not hinder participation, such as bowls and croquet. This particular strand of the project has become so successful that the school now hosts monthly events in partnership with external organisations, such as Age UK and the Alzheimer’s Society. This type of collaboration has spurred the development of further projects for the students to exercise their dementia knowledge outside of the school environment, such as by becoming buddies to dementia suffers living in a local care home and helping them to live well.

The programme also aims to raise awareness and increase understanding of dementia in the community through a bottom-up approach. The pupils present at conferences, use their artist skills to make short films to be used by the media displaying what it is like to live with dementia, whilst also creating also making posters advertising Plymouth as dementia friendly.

**Where / who:** Pupils and staff of Stoke Damereel Community College situated in Plymouth, England. The school is part of a network of 21 schools wide named Dementia Pioneer Schools, each challenged by the Prime Minister to incorporate education about dementia across the whole curriculum.

**Benefits:** This educational programme benefits those with dementia and the members of the school to equal measure, whilst also creating a tested educational model which could be rolled out into other schools. The pupils and teachers understanding of the condition is enhanced through the variety of methods and topics, encouraging them to take a holistic perspective when understanding the condition and become experts through own experience. This bottom up approach to spreading awareness and nurturing understanding is fundamental to the longevity of the project as these children can act as lifelong advocates for dementia care within a community setting.
Students playing croquet with local residents with dementia

Year 7’s playing music to those with dementia as part of Dementia Awareness Week