

# *Supporting persons with dementia and their families*

*Good practice from Eurodiaconia members*

**APRIL 2015**

Eurodiaconia is a **dynamic**, Europe wide **community** of organisations founded in the **Christian faith** and working in the tradition of Diaconia, who are committed to a Europe of **solidarity, equality** and **justice**. As the **leading network of Diaconia in Europe**, we connect organisations, institutions and churches providing **social and health services and education** on a Christian value base in over 30 European countries.

We bring members together to **share practices, impact social policy** and **reflect on Diaconia in Europe today**.

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## INTRODUCTION

Eurodiaconia is a dynamic, Europe-wide community of social and health care organisations founded in the Christian faith and working in the tradition of diaconal service, which are committed to promoting social justice. It represents more than 40 members working in over 30 countries, including churches, not-for-profit welfare organisations and NGOs. Eurodiaconia links its members to examine social needs, develop ideas, influence policies and promote a social Europe. Together, they work to enable inclusion, care and empowerment of the most vulnerable and to ensure dignity for all.

One of Eurodiaconia's three pillars of work is "Praxis", and one of the main goals in this area of work is to facilitate mutual learning among members and help them create strategic partnerships. One way Eurodiaconia does this is by disseminating information on effective and perhaps innovative services and/or projects in specific fields that members run. This brochure presents comprehensive information from our members on a cross-section of services for and initiatives relating to persons with dementia, gathered through interviews and information online. We hope that organisations can draw inspiration from the examples, form ideas for new initiatives or further develop existing services.

Within each case study, we have highlighted the goals of the project, the methods, the type of funding used, and recommendations for others to consider if they are interested in implementing a similar project or service. We have also highlighted the most challenging aspect of the project, how this can be overcome, as well as what might be the most unique aspect of the project in order to

allow readers to understand the most important elements of each featured case. We also draw out key themes from the examples, to emphasise important aspects of the work in this field.

This brochure also serves as a showcase for the work of diaconal organisations among decision makers and strategic partners, raising awareness of their innovation and commitment to ensuring that persons with dementia can live in dignity.

### Key findings from the case studies

In all of the cases below, a key theme emphasised by members is the need for **an individualised, person-centred approach to care**. Services and products are tailored specifically to their environment, physical abilities, familial situation and the degree of dementia they are dealing with. This individualised care **must allow for the service user's participation and input** in all major aspects and stages of care and the development of care solutions.

**Partnerships** have also been highlighted as an important element for the services and initiatives contained in the report. They ensure that as much expertise as possible is brought in, and that all possible synergies are taken advantage of. Partnerships range from IT companies, Alzheimer's associations to local cafés and schools.

**Awareness-raising** and the subsequent **breaking of taboos** with this issue was another important aspect emphasised in many of these projects. Our members have worked with students, local sports clubs,



volunteers, and theatre productions to help make dementia a more approachable and understandable topic within today's society by connecting people. Our members hope that more people from the general public will interact with those that suffer from dementia to foster their social inclusion and to remove stereotypes and the negative impacts of stigma.

Another key aspect of many examples is an **integrated, comprehensive approach**. Dementia impacts many areas of life and therefore often many different specialists or services are needed. Various methods of coordination are used in the examples that follow, from nurse case managers to low-threshold community centres. For more

information on the topic of integrated care, Eurodiaconia's recommendations for integrated care can be consulted in this document.

Finally, many of the persons interviewed expressed the **challenge of ensuring funding** for their work. Members report that it is easier to get funds to start the work than to sustain the work, despite the fact that the service or initiative is successful. That is why a number of projects draw funding from numerous sources to enable them to keep operating. Publicity and raising awareness of the work is also important to ensure support.



## CASE STUDIES FROM EURODIACONIA MEMBERS

### Austria

*Diakonie Österreich / Austria [www.diakonie.at](http://www.diakonie.at)  
member Diakoniewerk Gallneukirchen /  
Salzburg [www.diakoniewerk.at](http://www.diakoniewerk.at)*

#### 1. Diakonie Dementia Counselling Centre in Salzburg ([www.demenzinfo.at](http://www.demenzinfo.at))

A member of Diakonie Austria, Diakoniewerk, runs a “Dementia counselling centre” in the city of Salzburg where carers of dementia patients can come for advice on therapies, activities or programs to help their relative on a day-to-day basis. This centre also works diligently on “awareness-raising” activities throughout the city, educating the public on what dementia is, what different degrees of dementia look like and how to better interact or communicate with someone who has dementia.

#### Integrated care

In Salzburg, Diakoniewerk operates a day-care centre, a hospital, an older home and a homecare service for older people. The dementia counselling centre acts as a liaison between these different services and can help guide relatives and carers of those with dementia towards an appropriate therapy, program or activity. This counselling centre also allows family members to have easy access to important information related to their loved one’s disease. For example, relatives can easily call in and have their questions answered: what the procedure is when a person with dementia is transferred to an

older home or to a hospital for care, ideas of different kinds of activities that encourage a person with dementia to do some daily routines on their own, and guidance with how to best communicate with that particular loved one with dementia. In the counselling centre, people needing advice can walk in and talk to a psychologist, medical professional or care-worker or they can easily phone in to the centre and receive advice from one of these professionals. Because of the wide range of skills of those working at the counselling centre, almost all issues or topics related to dementia can be dealt with directly, and a person needing advice can be guided to the appropriate service (day care, homecare, older care) if need be. Diakoniewerk explains, “(at the counselling centre,) we can help those relatives understand how to communicate with their relative suffering from dementia, but if they want further treatment for their relative, we can also connect them to other local diakonia services that can directly help them and their situation.”

Diakoniewerk also stresses that a unique feature of this project is that relatives are able to get direct counselling and pertinent information in an easy manner. This centre fulfils a basic need for those relatives who are carers; it provides important advice to those carers who don’t know what step to take next. Diakoniewerk explains that “the combination of services and information counselling is the most interesting aspect of our project because we are able to direct people to helpful services as well as provide one-on-one counselling”.

## Reaching out to the local community

The dementia counselling centre in Salzburg has also released important leaflets about dementia to help educate the wider community. These leaflets are not only available in German but also in Bosnian/Croatian/Serbian and Turkish, as there are large groups of migrants from these two areas (Turkey and the former Yugoslavia) in this part of Austria, and these members of society may not speak German but might still want to learn about the disease their loved one is suffering from. The leaflets provide basic information about dementia and how to best communicate and encourage someone with dementia and can help a person of non-Austrian origin learn about projects or therapies operated by Diakoniewerk that could greatly help their loved one suffering from dementia.

## Financial support, financial challenges

The entire dementia counselling centre, including the creation of these leaflets, was funded by a private German foundation at the beginning of 2012. The project was funded under that foundation until the end of 2014, after which time the city of Salzburg began to help finance the project so it could still operate once the funding from the private foundation had ended. This is mainly due to the fact that the counselling centre has been successful in the last two years in involving the local community through events and helping relatives of those with dementia.

Finally, Diakoniewerk explains that the most challenging aspect of this project is acquiring financial security for the centre. They explain that the basics of care for a dementia patient

are provided by the state but not anything above that, so trying to find financial support for a dementia counselling centre that is outside of the “basic” level of care has been rather challenging.

## What's next?

In the future, Diakoniewerk says that they “would love to have dementia counselling centres in every town where Diakoniewerk has services. We are always trying to expand, and we are currently conducting dementia workshops and seminars in other Austrian cities that could spur support for an actual dementia counselling centre in one of these places”.



*A flyer advertising Diakoniewerk's dementia counselling centre and services (copyright Diakoniewerk).*

## 2. Theatre Production in Wels, “You are my Mother”

Each year, Diakoniewerk in Austria seeks to raise awareness about dementia by hosting some sort of event or workshop on World Alzheimer’s Day. Last year, on September 19th in Wels, Austria, for their “World Alzheimer’s Day” event, Diakoniewerk Austria decided to host a theatre production of the play “You are my Mother”.

### Identifying with dementia

The play showcases the relationship between a mother and son as the mother becomes more affected by her dementia. The play is portrayed by a single actor who constantly switches between the role of mother and the role of son. By constantly switching roles, the audience is shown how often times with loved ones who have dementia role reversals within the family unit have to occur, like when children may have to act more like parents to their own mother and father. As the actor switches roles throughout the play, the audience can see how emotionally and physically straining this role reversal is not only for him, but for any family dealing with the disease of dementia.

The play was free of charge and was open to anyone in the community. The goal of the event was to spread awareness about dementia and help make this disease seen and understood within the community. Overall, there were about 200 people who came and watched the play, including those suffering from dementia, relatives who have loved ones with dementia, social and medical professionals who assist those with dementia and many other members of the wider Wels society.

### The funding challenge

The theatre event was financially sponsored by several different partners including the city of Wels and the regional government of upper Austria. The government was willing to financially assist this project because it helps not only those members of society dealing with dementia, but it helps educate the general public in Wels about the different elements of this disease. However, Diakoniewerk explained that even though they eventually got all of the sponsors they needed for the event, the process of trying to find and secure this funding was the most challenging aspect of the project, along with acquiring the right theatre with the correct amount of seating for the play.

### Getting people’s attention

Overall, Diakoniewerk is very happy they decided to show a play to support World Alzheimer’s day last year. The event was much more “attention grabbing” than just a seminar presenting concrete facts about dementia. This play was able to reach into the hearts and minds of audience members and allow them to see the day-to-day challenges of living with dementia, either as the one suffering from the disease or as the caregiver. The play allowed society to step away from the medical/scientific parts of dementia that are most often talked about in classrooms or hospitals, and emphasise the familial and emotional aspects of dealing with this disease.

Diakoniewerk says that the event was so much more than a simple presentation about dementia; the play was able to present dementia in a playful way, with a few funny moments, a few sombre ones and many other

meaningful moments that demonstrate the complexities of the disease. By conducting a play, Diakoniewerk was able to gather members of society from all walks of life and let them chat and mingle. Furthermore, this event also gave them the platform to show the wider community in Salzburg a heartfelt story about dementia. With this play, dementia is not just a medical term, it is so much more than that as it shows the audience some of the realities of living with dementia. **Diakoniewerk emphasises that the most interesting aspect of this project** is the fact that it helps inform people about dementia in a captivating, playful way without being too academic. This play is a great way to get the local community involved and understand what life is like for those with dementia, and for those who care for loved ones suffering from dementia.



*A photo of the actor performing in “You are my mother” for the theatre night put on by Diakoniewerk in Wels, Austria, for World Alzheimer’s Day (copyright Armin Weber 2014).*

## Finland

Oulu Deaconess Institute [www.odl.fi/sivu/fi](http://www.odl.fi/sivu/fi)

### 3. “Gamified” Services for Older Persons, including those with dementia (GASEL)

Currently, society’s older population is living longer, meaning that in general, older people are needing more resources for a longer time than in previous decades to help them function properly throughout all of their senior years. The project GASEL (Gamified Services for Older) seeks to promote health and wellbeing among older people and provide them with a resource to use when encountering physical, emotional or social issues. This service will be able to directly help those people suffering from dementia as it will provide games and programs that will encourage the active participation of the user and will work towards improving that person’s physical and mental wellbeing.

#### Playing games

The project seeks to create e-Services which can be used by older people to help them maintain or improve their mental wellbeing. These e-Services would be “gamified” or shown as games; gamification is the process of increasing the user’s engagement and participation by integrating game mechanics into other services. Oulu Deaconess Institute explains that “e-Services, like applications for mobile phones, are becoming an important part of society, but there are not many developed currently that directly support the mental wellbeing of older people”.



The mobile application that GASEL hopes to create would facilitate social interactions, end-user activation and would be easy for older people to access. Furthermore, this application and its corresponding games could be tailored to an older person's capabilities, further promoting an individualised, high quality service for that particular individual. Traditionally, an older person or someone suffering from dementia may receive a certain physical or mental therapy once a week. By utilising e-services that can be accessed on mobile devices, those suffering from dementia can have daily, individualised therapies through these specific games that can help them improve their capabilities and overall wellbeing, without having to wait weeks on end for a specific staff member to carry out a particular therapy with them.

### **Partnership**

GASEL is a project with many different partners including: several research organisations, including Eurodiaconia member Oulu Deaconess Institute, The City of Oulu, Caritas Foundation Oulu, a few corporate partners as well as some international academic and IT partners. The entire project is funded by the Finnish National Technology and Innovation Agency (TEKES), and the funding lasts for all of 2014 and 2015.

### **Tailor made**

Currently, the way to create this mobile application is being researched by the different partners of the project through data collected from over 1000 questionnaire responses from older adults (ages 65 and above) about their likes and dislikes in utilising technolo-

gies as well as ideas about how technology could help support mental wellbeing for older people and those with dementia. By collecting all of this data, researchers in the project will be able to inform the IT companies that will create the future GASEL mobile application about how to tailor specific games to the needs of the older population as well as ways to help promote the utilisation of an e-service among older adults.

The most interesting aspect of this project according to Oulu Deaconess Institute is the fact that this mobile application will truly be tailored to the needs of the older population. They explain that "there is a lot of talk about (end-user) participation in many of these kinds of projects, but sometimes a user's participation in a trial only consists of saying 'yes I liked it' or 'no I did not like it'. Real user participation and success of the project depends on full and detailed input of the end user and we will be able to have the full input of the end users all the way through this research process".

### **The challenge of investment**

According to Oulu Deaconess Institute, the biggest challenge with the GASEL project has been trying to get businesses to support and market the idea of a mobile application supporting the mental and physical wellbeing of older people. They explain that "it is difficult to get corporations to back this idea, market it or publicly support it as there is little to no profit for them with this kind of information dissemination".

## Looking to the future

In the next stage of the project, Oulu Deaconess Institute is looking to secure funding from Horizon2020, the main EU research and innovation funding programme in this field. If funding is secured from this source, an actual mobile application will be able to be developed from all of the data and research that has been collected under the GASEL project during the last two years. Within this next stage, this mobile application will be created and piloted to a group of older people to judge its effectiveness and ultimately improve the e-service so it can better benefit the end users of the application, some of whom will be older persons suffering from dementia.



*This picture shows what a future GASEL mobile application for older people may look like.*

## France

*L'Association de Soins et d'Aides à Domicile de Colmar et Alentours (ASAD)*

[www.asad-colmar-asso.fr/relais.php](http://www.asad-colmar-asso.fr/relais.php)

*Member of the Fédération de l'Entraide Protestante* [www.fep.asso.fr](http://www.fep.asso.fr)

### 4. Specialist Alzheimer's team : Le Relais

In the framework of the national Alzheimer Plan for France 2008-2012, ASAD created an "équipe spécialisée Alzheimer" (ESA), a specialist Alzheimer team. This was one measure proposed by the government out of 44 different measures, and ASAD was selected as one of the 40 organisations from 151 applications for a pilot phase of this team approach in 2009 following a public call for proposals.

The mission of the mobile team is to support people with Alzheimer's or diagnosed with dementia-related symptoms and their carers. National meetings of people from the pilot teams and host organisations in 2010 enabled exchange of experiences, and the final results were evaluated. The approach was deemed to be successful and now the ASAD team, called "Le Relais", The Relay, works alongside more than 30 people, for a maximum of 15 visits a year. The state committed to put 500 teams in place across France, and the Alsace region now has its maximum number of 11 teams.

### Enabling people to stay at home

The overall objective of these teams is to enable people to stay at home. A personal project is drawn up with the family and beneficiary. There are a number of specific aims: to maintain physical and mental autonomy



as long as possible, enable the learning of compensatory strategies, reducing behavioural disorders, adapt the living environment to maintain or increase the potential of the persons and their safety, support and work alongside the carers, bring new perspectives to the carers, prevent hospitalisation or the need to go into residential care for as long as possible, and to ensure coordination with others when the team ends the support work.

### **A multidisciplinary team**

The team at ASAD includes a nurse coordinator, a psycho-motor therapist and occupational therapist, a psycho-medical assistant and two geriatric care assistants. There is also cooperation with the prescribing doctor to ensure medical coordination. The occupational therapist and psycho-motor therapist work at the home of the person with Alzheimer's and ensure, from once the person is diagnosed, therapy, a plan for the adaptation of the housing, cognitive rehabilitation and stimulation and, if need be in case of crisis, the management of behavioural disorders. The specialist team greatly improves the care of persons with Alzheimer's, their quality of life and that of those around them.

### **Partnership**

External partnerships are also very important in order to ensure a holistic approach. Le Relais works with, among others, general practitioners and specialist doctors, memory centres, day hospitals and day-care centres, nursing home care, social workers, household service suppliers, the Alsace Gerontological Network and the Association France Alzheimer. ASAD runs its own home help and household service organisation, carrying out household tasks and daily care. It also runs a nurses' centre.

### **The next steps**

There is now a plan 2014-2019 for neuro-degenerative illnesses, including people with Alzheimer's, Parkinson's and multiple sclerosis. The plan for developing ESAs includes continuing with the training and professionalisation of the teams and better identification of needs, including working with non-specialist home care services, for example enabling them to spot symptoms of a neuro-degenerative disorder. There is also the plan to involve a psychologist in the teams and test specialist team interventions for persons with other neuro-degenerative disorders, based on the ESA model.



## Germany

Diakonie Deutschland [www.diakonie.de](http://www.diakonie.de)

### 5. Diakonie Hessen

[www.moment-hessen.de](http://www.moment-hessen.de) “moment!: Motor and Mental Training” – Diakonie Hessen

As Germany has one of the oldest populations in Europe, and as many of these people suffer from dementia, Diakonie Hessen has recently developed a project to better engage those members of society who are suffering from dementia. In Germany, around 70% of people suffering from dementia live on their own or rely on care from their family members, so they often feel isolated and may not have the opportunity to participate in any kind of physical or group therapy due to their behaviour associated with their condition.

To overcome this problem, Diakonie Hessen has partnered with the federal state sports organisation to create a community-based approach to care for older people suffering from dementia. This care combines mental and physical training exercises and is called “moment!”. In “moment!” activities, those with dementia can take up certain physical activities that can improve both their cognitive skills and physical capabilities at their local sports clubs twice a week (if not more).

**Diakonie Hessen emphasises** that there has been research done that shows that sports and physical exercise has **preventive as well as therapeutic benefits** in relation to the progression of dementia. With this in mind, the main aim of the project is to **encourage those end-users who have dementia to participate in sports and other physical activities** by conducting safe, tailored exercise activities at local sports clubs or residential care homes. These group

physical activities help those with dementia not only physically, but mentally and socially as well. The activities are done in partnership with other members of the community, which enables those with dementia to lead more socially included lives within their own town or neighbourhood. Through these group exercises conducted in the “moment!” project, those with dementia are able to participate in sports with like-minded people, socialise, improve their self-confidence, discover hidden skills, and improve their overall body alignment and cognitive capabilities.

Another important aspect of this project is to **raise awareness about dementia** throughout the wider society in this area of Germany. By using local sports clubs to conduct the physical activities for those with dementia, the wider society, specifically those that visit the sports clubs, is able to understand better what it means to live with dementia and to normalise the condition. Furthermore, Diakonie Hessen has partnered other local diaconal groups, the German Alzheimer's Society, local sports clubs and residential care homes in order to expand the “moment!” project and allow more people with dementia to benefit from these physical and mental training activities.

Diakonie Hessen has helped **strengthen the possibilities for active participation in society for those who suffer from dementia and those family members who can become isolated as they care for their loved one who has dementia.**





*Volunteers, staff members and beneficiaries work together through this project to help empower those suffering from dementia through exercise therapies and socialisation activities.*

Those members of society who hear about the “moment!” project and are interested in helping expand the project can create their own “moment!” group in their town or neighbourhood. These volunteers can easily participate in a qualification programme in order to become a certified “moment!” activity operator and thus, can begin to operate their own “moment!” group. This training programme offered by Diakonie Hessen is a five-day intensive training course, highlighting mental and physical training methods that will give them the specific **qualifications needed to set up their own group**. There have been over 170 people who have gone through these training processes and numerous “moment!” groups have been set up throughout the Hessen region of Germany.

The most unique aspect of this project is that it prevents isolation and promotes independence of those suffering with dementia as it encourages group sports activities on a regular basis.

Diakonie Hessen explains that the funding of the project began in March 2010 and continues today. The funding in 2010 was acquired through financial resources from the German care insurance and the federal state government. Actually, Diakonie Hessen and the federal sports organisation applied for financial support through the Erasmus + programme

together with partners from Austria, the Netherlands, Finland and Turkey. Furthermore, according to Diakonie Hessen, the biggest challenge for this project is continuing to raise awareness about Dementia in sports clubs.

In the future, Diakonie Hessen hopes that more sports clubs will participate in the “moment!” project and more volunteers will become certified in conducting these activities. Also, Diakonie Hessen hopes to create a stress-reduction programme in the near future to go along with the physical activities for those with dementia. This stress-reduction programme will be tailored to those family members who act as primary carers for a loved one with dementia. Along with people who suffer from dementia, their family members and carers can often feel quite isolated from society; Diakonie Hessen hopes to expand the “moment!” project in order to assist these family members as well.

#### **6. Diaconal Social Centre in Rehau, Rummelsberger Services for Older People gGmbH, Rummelsberger Diakonie**

[www.altenhilfe-rummelsberg.de/standorte\\_rehau1.html](http://www.altenhilfe-rummelsberg.de/standorte_rehau1.html)

The Diaconal Social Centre in Rehau is the hub for a range of services for persons with dementia and their families. In 2014, the Centre won the 3rd prize for best dementia-oriented services from the German Alzheimer Society. The jury emphasised the broad range of services and the interplay of three dimensions: a residential care facility, home care and services for family care givers, as well as the large number of volunteers involved. The jury was impressed at how an organisation of the size of the Social Centre managed to coordinate such activities.

## Varied activities and services

The Social Centre is integrated in a residential area with its own park and is within walking distance from the centre of town and its amenities. It offers a daily programme of services, tours, seasonal festivals and other activities designed for individuals, aiming for a varied programme each day. A chiropodist, hairdresser's salon and pub can also be found in the grounds. Pastoral activities include daily devotions, church services and on request hospice accompaniments and blessings. There is also a support group for people dealing with grief. Just over 100 people are currently living at the centre, and around 20 people are staying in separate sheltered accommodation. Full-time and volunteer staff work in the centre. As well as residential care for persons with dementia, short-term, respite and day-care services are available. Home care services and household assistance services are also available, as are "meals on wheels".

The organisation manages support for those affected by dementia in order to allow people to live independently in their own homes as long as possible. In carrying out their activities, they aim to improve the quality of life for people in need of care and their families. Their work also develops community among carers outside of their family networks. Their home care-related activities are also a response to the political promotion of home care over residential care, to the pressure on finances and an increasing number of older carers, as well as the disappearance of family links.

## Equipping volunteers and family carers

The ROMEOundJULIA programmes provide support for people with dementia who live at home and their families, who often act as carers for the person with dementia. ROMEO and JULIA are acronyms in German for what translates as "Rummelsberg organises support for people where they are" and "all hours support for life in everyday life".



The ROMEO programme provides a 40-hour training certification for volunteers with the German Alzheimer Association, as well as further "on the job" training and reflection groups. ROMEO organises the placement of volunteers to care for people with dementia in their homes. In addition, they organise meetings for family carers and relatives, monthly training sessions and give them a place to exchange experiences and support each other as carers. The JULIA or "JULIET" programme organises volunteers to help people with dementia with everyday household chores like grocery shopping, going to doctors' appointments and gardening. It also provides a counselling service for issues relating to ageing, as well as case management and coordination work in neighbourhoods.

An advice centre and hotline are also available for consultation on dementia or ageing related issues ranging from dealing with the authorities, to writing living wills and/or adapting one's living environment.

## Italy

*Diaconia Valdese*, [www.diaconiavaldese.org](http://www.diaconiavaldese.org)

### 7. Ambassadors for Alzheimer's

In 2009, Diaconia Valdese in Italy began the “Ambassadors for Alzheimer’s” project at the “Rifugio Re Carlo Alberto” Centre, which is located in the countryside of Italy outside the city of Turin. This building began helping older people back in 1898, but since the year 2000, this centre has specialised in caring for those older patients suffering from dementia. After reflecting on some of the needs of the dementia patients utilising the centre, it was decided to begin this “ambassadors” project in order to create more awareness in the local community about dementia and to also help those suffering from dementia in this region lead more socially included lives. Furthermore, with this project, those at the Rifugio Re Carlo Alberto wanted to help not only those suffering from dementia but also the so many family members who act as primary care givers for relatives suffering from dementia. A final central goal of this project is to empower those with dementia by “celebrating what is possible” in their lives and encourage them to have goals and to work towards them.

#### The holistic approach

The project is composed of several different activities or services that take place in and through the Rifugio Re Carlo Alberto. All of these services seek to promote good, quality care of those with dementia and the dissemination of correct information about the disease to the wider community. Through this care and awareness raising, more “Ambassadors for Alzheimer’s” are created throughout

the society. Diaconia Valdese says that the entire philosophy behind the Rifugio and the Ambassadors project is to “serve the people (or end users)”. They emphasise that any methods, activities or services that are run must be constantly adapted to fit the needs of the end user in order to create the individualised, person-centred care they desire.

One of the services “Ambassadors for Alzheimer’s” runs is a day centre that is able to provide a short break for primary care givers as well as essential physical and mental therapies for patients who suffer from all different phases of dementia. This project also operates a home care service where care professionals can come directly to those patients who are suffering from dementia; furthermore, “Ambassadors for Alzheimer’s” sponsors home-based training sessions, where care professionals can educate primary care givers on how to best communicate with their loved one who is suffering from dementia. In this training, care professionals are also able to give family members ideas for activities that will help support the physical and mental health of the family member with dementia. Through this project, Diaconia Valdese also hosts information and dementia awareness training events in the local community, one example being the seminar “Us with You: The Wandering Mind”, helping those members of society not directly involved with dementia patients learn more about the intricacies of this disease.

#### The reach of the project

Since 2009, “Ambassadors for Alzheimer’s” has directly worked with 265 people suffering from dementia; furthermore, it has done over 25 personalised trainings for families with loved ones at home suffering from



dementia. Furthermore, over 1000 members of the public have participated in some of the community-wide informational events hosted by Diaconia Valdese through this project. This project is run not only by Diaconia Valdese, but also with Bottega del Possibile (Boutique of the Possible), ASL TO3 (the local health authority) and local government authorities to help with the logistical elements of some of the activities run by the project. The project is funded by the “Compagnia San Paolo” and from the Otto per Mille foundation of the Waldensian church.

According to Diaconia Valdese, “the biggest challenge with this project is working for a cultural change in our community, in partnership with local stakeholders, in order to create an ‘Alzheimer’s Friendly Community’, with the goal of less loneliness for people at early stages of dementia and their families. Beside this, another goal of the project is to continue to carry on our services while constantly adapting and adjusting them to the needs of the people with dementia and their relatives, families and care givers”.

The most unique aspect of this project is the fact that it supports the integration of those people who suffer from dementia by directly training their families on different activities they can do to improve their quality of life and interact more fully with society. Also, this programme gives a voice not only to people who suffer from dementia, but also to their families and care givers, who can sometimes feel very isolated from society as their care giver role occupies much of their time and energy.

*This is the Rifugio Re Carlo Alberto, a centre run by Diaconia Valdese that supports people with Alzheimer’s and helps their families in becoming “Ambassadors for Alzheimer’s”.*



### **Promoting understanding for inclusion**

Overall, through the “Ambassadors for Alzheimer’s” project, some of society’s negative prejudices and stereotypes about people with dementia have been able to be countered, which is crucial when trying to help those with dementia achieve more socially included lives. Diaconia Valdese explains: “We have been very pleased with the way in which a project begun by our front line people has continued to develop and evolve over several years, incorporating new features and services. An example of this is a new initiative launched in March 2015 entitled ‘A community which welcomes and includes’, aimed at further building awareness and understanding in the local community about Alzheimer and dementia. Given the success of the “Ambassadors for Alzheimer’s” project, the CSD has decided to use this model in other areas of its diaconal work.”

## Norway

*The Church City Mission Oslo*

[www.bymisjon.no/Support/English-Site](http://www.bymisjon.no/Support/English-Site)

### 8. “This is my life”- a student/older person collaboration

This project run by Oslo City Mission involves 12 year-old students working with people who have dementia in a local older home to create a book about the person's life. The project began when Gudmund Fosse, an advisor in Oslo City Mission, was brainstorming ideas on how to enhance the identity and self-esteem of people with dementia living in a nursing home. The creation of “This is my life” books was one of the ideas that came about from this brainstorming period. These books outline key events and situations about the person with dementia's life and the aim is to help the staff members in the nursing home as well as the resident as it easily presents details about that person's life that can assist with therapy exercises and communication issues.

#### Participation and bridging gaps

Not only did Oslo City Mission want to help people with dementia create books about their life to help them remember and look back at key events, but they wanted to make sure that the person with dementia was involved in every step of the project, giving them a sense of responsibility and self-worth in the process. To create the books, Oslo City Mission thought it would also be important to bridge the “age gap” and have children interact with these people to learn more about the lives of the previous generations. Oslo City Mission says their goal for the project was twofold: 1) How can we make people with dementia feel important and that they are still an integral

part of society? And 2) How can we integrate different cultures and generations in Norway, letting our younger generations learn valuable information from the older one?

#### Facilitating the intergenerational exchange

To begin this project, Oslo City Mission contacted local schools and told them about their project proposal. After finding a local school (Gamlebyen skole) and a City Mission nursing home (St.Halvardshjemmet) to partner with for this project, Oslo City Mission took the next year with their partners to effectively plan the implementation of the project. After all of the planning took place, the creation of the actual books occurred in the second year of the project. During this year, 10 older people with dementia and 30 different students were involved in the project. Three students would meet together with older persons and interview them for the content of the autobiographical book. The children would prepare questions to ask the person in advance of each meeting, and in between meetings, students would contact the person's loved ones to get pictures from their childhood, from their adult life or to find out more important stories about the person's life that could be included in the book.

**The most unique aspect of this project** is the creation of a space where children and older people can freely interact, empowering both groups. This intermixing of generations teaches the children about respect and how to be kind to an older person. This project can be easily transferred to another country, into another language or another culture. According to Oslo City Mission, “all you need for the project is a willing older home and school with teachers and staff who will help partner with you”.

This project has also benefited the children involved, widening their worldview. Some of the children involved with the project have started visiting the person they have worked with even outside of their regular school meetings. Through this project, children involved were able to learn about graphic design, Norwegian history and traditions (from the stories told to them by the older person with dementia or their family members).

### Focus on the positive

According to Oslo City Mission, the biggest challenge of the project was dealing with the memory capabilities of the person with dementia. Some of the people with dementia would remember a lot about their childhood, and others would remember almost nothing. The solution to this challenge was to constantly focus on what the persons could remember, so that they could still feel empowered and important, and to fill in any remaining blank spots in the book with information from relatives or loved ones.

### Expanding the activities

The project was funded by an innovation foundation in Norway that allows NGOs to send in unique project proposals to possibly be funded. But after the “pilot” two-year phase of the programme that has just occurred, Oslo City Mission emphasises that this project would not be expensive for another organisation to run as the meetings between the children and older people with dementia are cost free, and the creation of the books can be quite cheap and possibly incorporated into the costs of the child’s curriculum.



*Students sit with participants from the “This is my life” project that is run in part by Oslo City Mission in Norway.*

In the future, Oslo City Mission would like this project to be a yearly activity among other schools and nursing homes in Norway. There is currently a lot of interest among other NGOs and public bodies in Norway about implementing this project, and in June 2015, Oslo City Mission will present this project at the largest health conference in Norway. After this conference and continued conversations with government bodies in Norway, further implementation of this project in other schools and nursing homes throughout the country may be possible.

### 9. Grønn Omsorg i Storbyen, Green care – an active and meaningful life on the farm

[www.bymisjon.no/Prosjekter/Gronn-omsorg](http://www.bymisjon.no/Prosjekter/Gronn-omsorg)  
[www.bymisjon.no/Support/English-Site](http://www.bymisjon.no/Support/English-Site)

The Oslo Church City Mission runs an innovative day-care scheme for older people with dementia, which offers them the chance to work on a farm for three days a week. This means that they continue to have an active and meaningful life in the company of a group of friends, and gives their permanent carers some time off. The Grønn Omsorg i Storbyen (‘Green Care in the City’) scheme was launched in 2009 as a three-year pilot, and in 2013 was given a permanent budget by Oslo city council. It is funded under a contract which provides for a standard daily fee, and costs much the same as conventional day-care.

## Providing meaningful activities

The idea for 'Green Care' came about in 2007 when Anita Ellefsen of Oslo Church City Mission had a phone call from the wife of a dementia sufferer. He was in his 60s and had led a successful working life, and his wife wanted to find a way in which he could continue carrying out an active and meaningful activity. "He is used to acting to solve problems, not talking about them," she said. This set Ms Ellefsen thinking about what sort of setting could provide people with a cognitive impairment the opportunity to be active and lead a meaningful life. Norway has a centuries-old tradition of farms accepting visitors, mainly groups of children and people with psychological problems. So she wrote a project proposal and approached the county governor, knowing that he had extensive networking contacts. The conversation went well, but Ms Ellefsen then had to find a suitable farm. She eventually found Tori and Jon Ivar Bakke who run Skjerven Farm in Maridalen, 10 km north of Oslo city centre.



The Grønn Omsorg i Storbyen ('Green Care in the City') project offers day-care for three days a week for seven people between the ages of 55 and 75 suffering from dementia. Clients are assessed before being accepted, and they have to be fit enough to walk, care for themselves and work in the open air. They benefit from being in

*This picture shows the owners of the farm, Tori and Jon Ivar Bakke who help run the Grønn Omsorg i Storbyen ('Green Care in the City') project.*

a community of friends, and from undertaking a variety of activities, including tending to the sheep and horses and walking in the countryside. Transport and meals are also included in the funding provided by the municipality.

This scheme allows clients to stay at home with their families for much longer as it gives their everyday carers a much needed break. According to Oslo City Mission, an important aspect of this project is not so much that people with cognitive impairments work on a farm, but that they are not excluded from society when they do it.

## Learning and expanding

After the three-year pilot period, Oslo City Council decided to further the project by expanding this day-care service to other farms. The city council was keen to expand the project possibly because of the good job Oslo City Mission did documenting the successes and failures of the first "pilot" farm they set up. "One thing we did that no one else did was to use the pilot farm as a learning process. We gave regular reports to the municipality which identified both the uniqueness of the farm as a location and also the problems we were facing," she says. This learning has been institutionalised and has helped the project expand.

The city's population is around 600 000, and seven day-care farms do not fully meet the needs of that size of population. However, one of the challenges of this project according to Oslo City Mission has been to find the right farmers and land for the continued expansion of the project. "It is not an easy job. In fact, it's a double job, and you have to like people a lot. So we would need to find farmers who are suited to it," Ms Ellefsen says.



## Serbia

*Ecumenical Humanitarian Organisation*

[www.ehons.org](http://www.ehons.org)

### 10. EHO Homecare Service for Older Persons

The Ecumenical Humanitarian Organization (EHO) in Serbia runs a homecare service for older people, some of whom suffer from dementia. The homecare service provides social and medical assistance to people suffering from dementia by having qualified nurses and volunteers go to the clients' homes and help them with everyday chores. These nurses and volunteers not only provide help with household tasks, but they can also emotionally help some of these patients who may not receive visitors. By conducting quality, one-on-one or two-to-one care, EHO's homecare service is able to provide individualised, quality care to their clients and directly improve their quality of life.

#### The person-centred approach

For every beneficiary, an individualised plan is created between the nurses, doctor, user and family members. By planning the treatment activities directly with the beneficiary, the end-user is able to actively participate in the designing of his or her therapy plan. EHO explains that "with dementia, there are so many different stages. At the beginning of the disease, a client may just need help in small areas, however, at the end stages of the disease, a person may need help with every task. Therefore, the care for a person in our homecare service must be individualised in order to be truly effective."

EHO emphasises the holistic care available for the service user with this homecare

service. For example, in this service, EHO still uses volunteers who are able to visit the beneficiaries when needed. Sometimes a nurse may not have time to go on a walk or simply socialise with a beneficiary, but a volunteer can easily do this. By utilising both medical professionals and local volunteers, the care for these people becomes more holistic, providing not just medical and physical help, but social and emotional help as well.

Through their homecare service, EHO was able to conduct 13,000 home visits and have interactions with 170 beneficiaries on individual basis with qualified nurses and doctors at a minimum of three times a week in 2014. Currently, EHO employs 17 nurses, and 8 new nurses are being added to the team as a result of financing from the local municipality in Serbia.

#### Plans for the future

EHO explains that "in Serbia, there are not care homes for people with dementia and the care homes that do exist for older people do not provide specific services for those with dementia". In order to tackle this issue, EHO originally (prior to 2008) created a homecare service that utilised volunteers who would visit older people suffering from dementia in their homes. However, these volunteers were not able to provide some of the medical care needed. So in 2008, EHO decided to also employ nurses in this homecare service in order to make the service even more beneficial to the end user. Now, the overall goal of the project is to provide a service to beneficiaries that is currently not available in Serbia (as there are no specialised older homes): high-quality, individualised care for older people, including those who suffer from dementia.

This project was funded in part through international donors from Germany and Switzerland. The project is also partly funded by the Serbian government and partly by the beneficiaries themselves. EHO explains that securing financial security for the project is the most difficult aspect of implementing this homecare service. However, recently, EHO received a promise from the Serbian government and from international donors that they would continue to fund the service for the next few years.

After the next three years, EHO hopes that the service will be more financially sustainable by opening a separate social enterprise to provide the funds for the homecare service. EHO is hopeful that the Serbian

government will give them some funding to help start a social enterprise that will fund this project. The legal framework for social enterprises in Serbia is currently being finalised by the government, and EHO hopes to be one of the first social enterprises registered within this framework. After registration, EHO hopes to be able to apply for public funding to set up the social enterprise.

EHO is trying to acquire a national license for this service, which would help EHO acquire state funding and even more interaction with state officials. EHO is hopeful that by the end of 2015 this homecare service will be officially licensed and will be able to access more state support and recognition throughout the country.



*This is a couple in Serbia who uses EHO's homecare service. As the husband suffers from dementia, it is very difficult for his wife to carry out normal activities. They explain that the homecare service that EHO provides to them has helped them continue to live as normally as possible in their older years.*

## Sweden

ADIS- Bräcke Diakoni

[www.brackediakoni.se/situfundatia/in-english](http://www.brackediakoni.se/situfundatia/in-english)

### 11. Person-centred documentation and evaluation (PDE) supported by ICF (International Classification of Functioning Disability and Health)

Bräcke diakoni started a project called **PDE – person-centred documentation and evaluation**. The aim of the project is to increase and help guarantee high-quality, person-centered care for persons suffering from dementia and living in care homes. Going beyond the commonly collected biomedical information (e.g. disease burden, diagnostic tests), staff use the International Classification of Functioning Disability and Health (ICF) from the World Health Organization (WHO).

#### Understanding capabilities

The ICF provides a viable code set for describing health and functioning in a structured and systematic way. Furthermore, it integrates the biological, individual and social perspectives on health and comprises not only body functions and structures but also an individual's activities and engagement in life situations as well as individuals' environmental and personal factors. By using the ICF, the staff is able to describe individuals' functioning in a holistic way, not only describing their problems but also acknowledging the resources they have. The starting point for this project is always the individual's own experiences and perspective on what creates meaning in their lives.

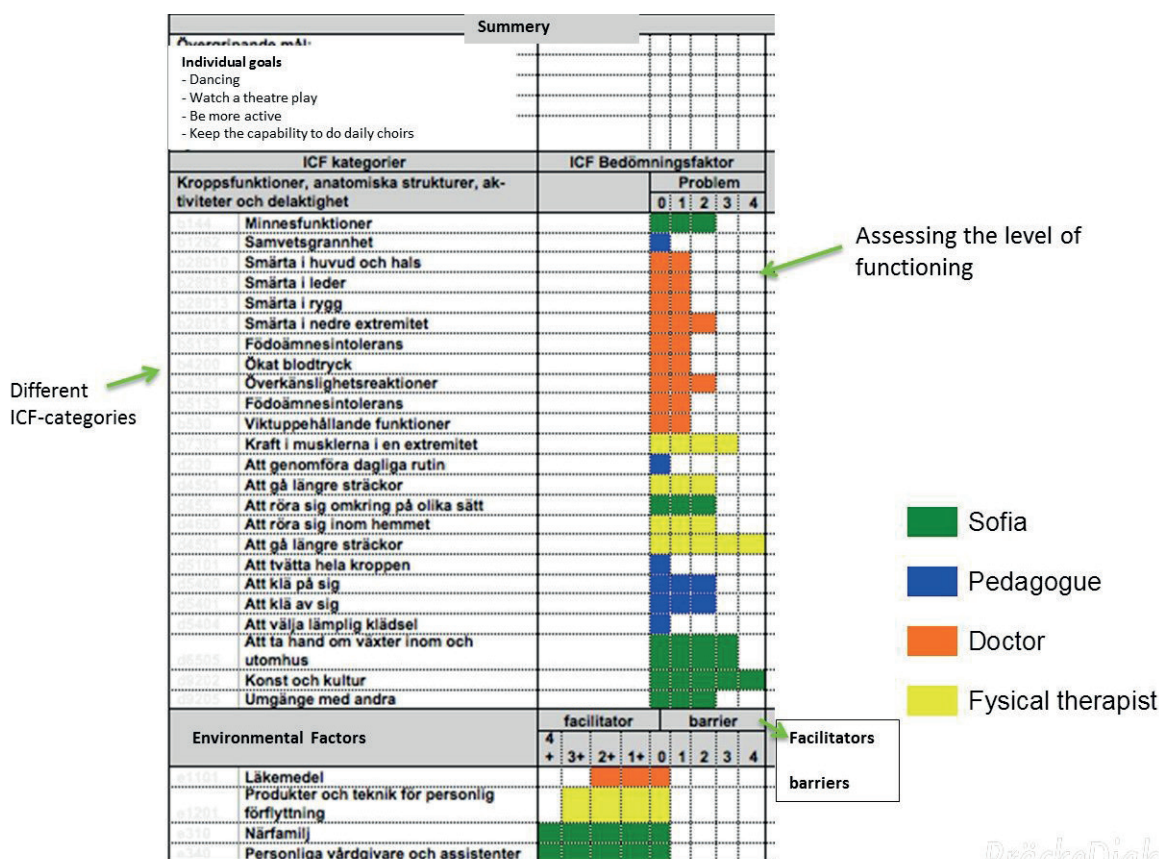
As the ICF provides a category for each of the many aspects of health and functioning, it is possible to summarise the information in charts (see page 24). This overview offers a comprehensive “snapshot” of individuals' functioning. With this overview, staff is able to describe individuals' functioning and generate hypotheses on whether one aspect of functioning is associated with another. Staff can then find patterns and identify aspects that should be addressed in order to reach individual goals. This working approach is characterised by a partnership between the persons themselves, their families and professional care providers creating personalised, coordinated and enabling care. Bräcke diakoni explains, *“Our aim is to do the PDE process with the residents and help them capture their own goals in an understandable way. We will use diagrammes, sounds or smells to reinforce individual goals if the end-user cannot communicate with words”*.

Often times when a person, suffering from dementia, moves into a residential care home, the person or family members can make a long list of all the things the person can no longer do. Bräcke diakoni has focused on using PDE and the resulting diagramme to show a person's resources and all the things they can still do, regardless of their diagnosis. As a result, 50% of the persons involved with PDE improve mentally and physically. Sometimes clients are more independent as a result of this treatment, thus requiring less care, and sometimes they are even able to move back home.

*“The most important part of the PDE is a partnership between the person and professional staff members”.*







*This overview offers a comprehensive “snapshot” of individuals’ functioning and ways different therapies and care professionals can interact effectively with the persons’ different levels of functioning.*

## A common language

Since ICF integrates different perspectives of health and functioning, it can also be used as a common language for different disciplines in care, bridging the gap of information exchange between different individuals, their families and health care professions, as well as between health and social care services and therapies. In that way, teamwork and coordinated care are facilitated.

## Partnership

The PDE project is carried out by four different partners: Bräcke diakoni, FAMNA (The Swedish Association for Non-Profit

Health and Social Service Providers), Jönköping Academy for Improvement of Health and Welfare (Jönköping University), and a Swedish IT company (Alkit Communication). This project is financed partly by a Swedish innovation agency (Vinnova) (50%) and partly by the four partners (50%). The funding for the project has been secured for three calendar years (2014-2016), but there is a goal among the project partners to make the project mainly self-sufficient by the end of 2016 (i.e. all of the IT work would be finished), making sure that the only cost after this point for running the project will be training new staff on how to work with PDE.

## The challenges of a new system

According to Bräcke diakoni, there are a few key challenges with carrying out this project. First of all, since the IT-support program is not complete from a technological standpoint, the staff at the dementia care homes have to realise that they are working on a pilot project, one that is constantly evolving and not perfect. The IT system needs to be developed further, and the project partners rely on the staff to explain when things with the project do not work right. Furthermore, for a staff member to truly understand the process of PDE, the system of ICF and its corresponding codes that are used in this project, about half a year of training is needed. This training in working with ICF will eventually be mandated by the Swedish government as public officials have recently stated that ICF care is the way forward in Sweden. However, it may be difficult for some organisations to carry out this project right now if they do not have the financial or staff resources to carry out this kind of training on ICF codes and mapping.

## A person-centred approach is essential

Bräcke diakoni emphasises that with this project, an organisation must always focus on the individual's specific needs. If ICF mapping becomes a way to make individual treatment for a person but is done without an active partnership with the person and his/her family, real improvements will not occur. The main point of PDE is to get clients involved in their own care, by helping them identify their capabilities and enhancing their independence and self-esteem through meaningful activities.

## UK

*The Church of Scotland Social Care Council,  
CrossReach*

[www.crossreach.org.uk/heart-art-0](http://www.crossreach.org.uk/heart-art-0)

## 12. Heart for Art

Significant international research has identified that there are enormous benefits to using creative arts. This enables people with dementia to connect with society and express themselves, whilst breaking down the barriers of preconception, stigma and discrimination. Encouraged by their professional art tutors in classes, the artists (some very experienced and some budding enthusiasts) have used their imaginations and life experience to produce each individual and unique piece.

The National Dementia Strategy for Scotland predicts a huge increase in the number of people with dementia over the next two decades. CrossReach have a history of innovation in dementia care, opening the first service exclusively for people with dementia within a homely environment in 1983. The Heart for Art project continues this trend, focusing on citizenship and opening up another avenue in promoting the abilities and potential of people with dementia.

The project has been funded for three years by the Church of Scotland Guild, which provided funding for projects aiming to deliver creative arts activities to people with dementia within parishes to encourage community learning, promote creative active aging and reduce discrimination. CrossReach believes that the work addresses the issues of equality, faith in action and Christian witness.

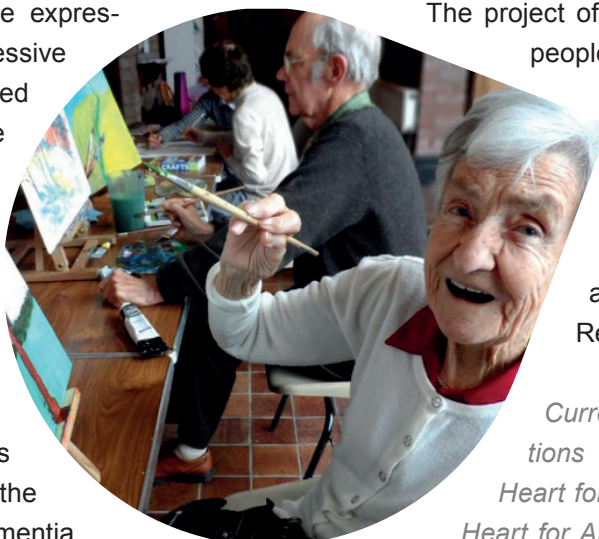
*"I have two sons who are both art teachers. I am looking forward to showing them my artwork as proof they got their talent from me".*



those living with dementia can still learn and preserve their human right to participate in society with dignity and self-fulfilment. At a private viewing of the exhibition in January 2015, the guests noted that they were genuinely impressed by the quality and diversity of the work on display. With the approval of the artists, CrossReach also had the pieces exhibited made into prints. *"It has benefitted his confidence in himself...he can see and feel that he can do things...that he is not written off"*, said the wife of one Heart for Art artist featured in the exhibition.

### Expression without words

When there are no words, and very often with dementia there is no word association when a person wants to express her/himself, the process of creating art enables the visible communication of thoughts and feelings. At CrossReach, the Heart for Art classes have frequently found that these expressions translate into impressive pieces of art and this ignited the initiative to showcase some of the inspirational pieces produced, and an exhibition featuring 40 artists was put on in early 2015 with their consent. The aims of the exhibition were to increase the awareness and understanding that the impact a diagnosis of dementia can have, to highlight and break down the barriers of discrimination and show that



### An approach with multiple facets

Heart for Art is designed through early intervention to promote creativity, self-worth and achievement. From the early stages of the project, the benefits of active lifelong learning (acting with purpose and increased concentration on creative tasks) have been visible.

The project offers the opportunity for people with dementia and their carers to build supportive relationships within the group and also access support and advice from CrossReach staff.

*Currently based in 7 locations throughout Scotland, Heart for Art is a story of Hope. Heart for Art is a story of opportunity when there seems to be no opportunity. Heart for Art is a story of "Can do".*





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