EUROFAMCARE

Services for Supporting
Family Carers of Elderly People
in Europe:
Characteristics, Coverage and Usage

EXAMPLES OF GOOD AND INNOVATIVE PRACTICES IN SUPPORTING FAMILY CARERS IN EUROPE

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EUROFAMCARE is co-ordinated by the
University Medical Center Hamburg-Eppendorf,
Institute for Medical Sociology,
Dr. Hanneli Döhner
Martinistr. 52
20246 Hamburg
Germany

doehner@uke.uni-hamburg.de

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Edited by Judy Triantafillou and Elizabeth Mestheneos on behalf of the EUROFAMCARE Group

The Members of the EUROFAMCARE Group

- Germany, Hamburg: University Medical Center Hamburg-Eppendorf, Department of Medical Sociology, Social Gerontology, University of Hamburg (Coordination centre) – Hanneli Döhner (Co-ordinator), Christopher Kofahl, Susanne Kohler, Daniel Lüdecke, Eva Mnich, Nadine Lange, Kay Seidl
- Germany, Bremen: University of Bremen, Centre for Social Policy Research – Heinz Rothgang, Roland Becker, Andreas Timm, Kathrin Knorr, Ortrud Lessmann / Centre for Applied Nursing Research – Martha Meyer
- Greece: SEXTANT Research Group, Department of Health Services Management, National School for Public Health (NSPH), Athens – Elizabeth Mestheneos, Judy Triantafillou, Costis Prouskas, Katerina Mestheneos, Sofia Kontouka, Anastasis Loukissis, Vickey Goltsi
- Italy: INRCA Dipartimento Ricerche Gerontologiche, Ancona – Giovanni Lamura, Cristian Balducci, Maria Gabriella Melchiorre, Sabrina Quattrini, Liana Spazzafumo, Francesca Polverini, Andrea Principi, Marie Victoria Gianelli
- Poland: Department of Geriatrics, The Medical University of Bialystok, Insitute of Social Economy, Warsaw School of Economics and Institute of Philosophy and Sociology, University of Gdansk – Barbara Bien, Beata Wojszel, Brunon Synak, Piotr Czekanowski, Piotr Bledowski, Wojciech Pedich, Mikolaj Rybaczuk, Bozena Sielawa, Bartosz Uljasz
- Sweden: Department of Health and Society, Linköping University – Birgitta Öberg, Barbro Krevers, Sven Lennarth Johansson, Thomas Davidson
- United Kingdom: SISA - Community Sciences Centre and School of Nursing & Midwifery, Northern General Hospital, University of Sheffield – Mike Nolan, Kevin McKee K, Jayne Brown, Louise Barber
- AGE - The European Older People’s Platform, Brussels, Belgium – Anne-Sophie Parent, Catherine Daurèle, Jyostna Patel, Karine Pflüger, Edward Thorpe

The Members of the International Advisory Board

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- Joseph Troisi, University of Malta, Institute of Gerontology, Msida
- Lis Wagner, WHO - European Office, Copenhagen

The Members of the Pan-European Group

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- Malta, Joseph Troisi, Marvin Formosa, University of Malta, Institute of Gerontology, Tal-Croqq, Msida
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- Spain, Arantza Larizgoitia Jauregi, Mungia, Bizkaia
- Switzerland, Astrid Stuckelberger, Philippe Wanner, Public Health - Department of Community Health and Medicine, University of Geneva-CMU-IMSP, Geneva
- The Netherlands, Kees Knipscheer, Geraldine Visser-Jansen, Free University, Department of Sociology and Social Gerontology, Amsterdam

EXAMPLES OF GOOD AND INNOVATIVE PRACTICES IN SUPPORTING FAMILY CARERS IN EUROPE:

Selective cases drawn from the EUROFAMCARE National Background Reports (NABAREs)

Introduction

One aim of the EUROFAMCARE project http://www.uke.uni-hamburg.de/eurofamcare/ was to collect together examples of good and innovative practice in the support of family carers in Europe. The 23 national experts, when writing their background reports on the situation of family carers in their country (NABAREs), were requested, in the standardised protocol (STEP), to provide descriptions of examples of both good and innovative practices, including post-caregiving services in case of death or the institutionalization of cared for persons, new technologies etc. The Pan-European Background Report (PEUBARE) (Mestheneos, Triantafillou 2005) which provides an overview of the 23 NABAREs (19 EU MS) written in 2003 - 2004, selected some of these descriptions to illustrate how the different countries had approached the issue of family carers and services for their support.

This overview illustrates the different stages of development of good and innovative practice in the European countries. Examples mentioned in one country as good or innovative might not be mentioned at all in other countries, not only because they are not available, but also because they are already established as a regular service.

The selection of examples of good and innovative practice is influenced by the authors' personal views and knowledge and by the selections originally made by the national experts. All members of the EUROFAMCARE project form a Pan-European Network in research on informal care, which will be linked to the movement for a wider network on research and practice under the umbrella of EUROCARERS - European Association Working for Carers.

This report on Good Practices is a collection of edited descriptions from the NABAREs under the country headings; some have contact details. Readers wanting further information should examine the original national report and if necessary contact the authors, the national experts.

Austria – AT

The examples focus on the improvement of co-ordination, at management level, between the different intramural and extramural professional services and agencies.

Good Practice

"Citizen Bureaus for the Young and the Old" (Bürgerbüros für Jung und Alt) have been established as a top-down initiative by the federal government to promote volunteer work. More than two dozen of them are in operation covering almost all provinces. These offices function as exchanges and clearing-houses for voluntary and charitable work. The idea is to create locally based and autonomous generation hubs of old and young volunteers working on social projects,

for example providing care for the very old or very young, friendly visiting, help with minor repair work, etc.

The "Memory Clinic Donauspital" in Vienna was established to serve dementia patients (especially those diagnosed with a mild cognitive impairment in its early stages) and their family carers in order to avoid institutionalization as long as possible. The average age of patients is between 65 and 70 years. Relatives get psychological counselling and information about possible family predispositions. In guided group discussions, carers have a chance to exchange experiences and express feelings of aggression, despair etc. which may be caused by caring for cognitively impaired parents or other family members. To develop coping strategies for those caring for dementia patients is a central goal, including recognizing and protecting one's own physical and mental health when taking on burdens. In co-operation with the Alzheimer self-help group (Alzheimer Angehörige), training courses are held four times a year. The aim is to educate family carers to be "co-therapists" at home (Rainer et al., 2002).

A range of other training programmes – mostly organized by non-profit welfare associations – exist for family members caring for elderly relatives.

Innovative Practice

One innovation in service provision is called "Integrated Health Care and Social Services Districts" (Integrierte Gesundheits- und Sozialsprengel[1]) which has a twofold purpose. First, to ensure co-ordinated high-quality care with full geographical coverage through the provision of medical, nursing and social services in small area units, and second, to expand preventive health care and health promotion. The Federal Institute for Health designed a basic model containing proposals and a manual for the organizational establishment of such service districts. In this model it is proposed that the services offered should be co-ordinated from district centres, in reasonably sized areas with about 10,000 to 20,000 inhabitants. The district centre should inform the inhabitants, provide help on the take-up of services, and also carry out community-oriented health work. The objectives of the concept are to improve and guarantee the provision of health and social care in a district; to co-ordinate and harmonize the services of health and social care organizations; to optimize co-operation and exchange between the health and social care organizations; to increase the effective output of the health and social care organizations in a district by catering to the special requirements of the patients; to help patients and their families to find the correct organization for their needs; and to initiate and develop health programmes. Only a few examples of this model project have been realized: the province of Tyrol offers information and advice for family carers, methodical instructions for better caring, respite services (including during the night), and supervision groups. Professional care for the elderly and counselling and training courses, etc. for family members are integrated (i.e. carried out by the same home health nurse). Other provincial governments or regional branches of health insurance have been hesitant to put this model into full action.[2]

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[1] This is the "official" label created for the model project; regionally varying designations are in use (if this type of centre exists at all).

[2] Regional and historic traditions means the implementation of nation-wide standard solutions is difficult to achieve. For instance, in predominantly rural Burgenland the development of community care structures is linked to small village develop-

Training courses contribute to making the family carers' indispensable care work easier; equally important, courses provide an opportunity to meet other family carers and to exchange experiences. One example is a course called **"Activation Programme to Promote, Reactivate and Preserve Cognitive and Motor Skills and for Sensitising and Training Sensory Modality",** designed to show older people and those who care for them – not only family members but also community care workers like home helps – how they can use targeted exercises to help the individual requiring care to preserve and improve their mental facilities, recover physical mobility and make conscious use of their sensory organs. After trials have been completed and the programme evaluated, multiplicator training courses will be held for the target group of family carers, and paid domestic carers working for social services, old people's homes and nursing homes.

The fact that people in urbanized areas are much more likely to die in a hospital than those living in rural areas, confirms that death in hospital is an indicator of modernization. Hospitals and nursing homes, however, are not designed for the dying as there is hardly time for a talk or love and affection. Since the 1970s critical voices have been raised about death in institutions. Nowadays, the trend is changing, towards terminal care in specialized institutions such as **hospices and palliative care** departments. Additionally, mobile hospice and palliative care teams are offering out-patient treatment (which enables patients to stay at home) and guidance of family carers. Some providers of in-home hospice services e.g. Caritas, Hilfswerk, offer special support programmes for family carers after the death of the old person.

Belgium - BE

Good practice

Integrated Services for Home Care (GDTs) is a federal initiative helping family carers by organizing multi-disciplinary consultations and helping them to draw up a realistic care plan that specifies the tasks of each formal and informal carer.

The Cooperation Initiatives in Home Care (SITs) were initiated by the Flemish

government in 1990 and bring together different carers (professionals, volunteers, family members), to work together, to confer and to make agreements. The goal is to coordinate the help the dependent person needs. The emphasis is on a holistic approach to the person and on continuity and good quality of care. One SIT per region of 25,000 inhabitants can be subsidized. The Flemish government plans on restructuring and renaming the SITs as SELs (Cooperation Initiatives First Line Health Care). These should coincide or cooperate closely with the GDTs financed by the Federal government.

Innovative practice

The Expertise-centres for Dementia are subsidized by the Flemish government.

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ment; in Vorarlberg there is a long-standing institution of locally based mutual home health care associations – as a result, the percentage of patients cared for by home nurses has always been much higher than elsewhere in Austria.

They give information and counselling to people suffering from dementia and their families and carers. Their vision is emancipatory: they want to help and reinforce the network around the person with dementia. They also organize lectures and training for formal and informal carers.

Small-scale normalized living for people suffering from dementia ('Cantous' in the Walloon Region, 'kleinschalig genormaliseerd wonen' in the Flemish Region). Scientific research showed that living in a familiar, safe and secure environment, supporting self-care, attention for the perception of the person, or encouraging participation in the broader society, significantly increases the life quality of a person with dementia. This encouraged several people to search for alternative deinstitutionalized forms of care for people suffering from dementia. These types of projects started in the 1980's and have attracted increasing numbers of supporters. Although projects are organized in different ways, their basic assumptions are the same. Dementia is seen as a pervasive issue for the person with dementia and for his or her environment. Life should still be worth living and this should be shown in the way people are treated i.e. with respect, attention, personalized, social, humane, recognizable and secure, integrated in the surrounding neighbourhood. The initiators were convinced that a small scale living environment would benefit a person with dementia, physically as well as emotionally. In our very cognitively oriented society, we tend to forget that a person suffering from dementia is more than his or her illness and that emotional consciousness is possible, even when our memory fails us. The initiators were convinced that a 'house in the row' would offer more chances of a continuing high quality of life than the classical nursing home concept. This however does not mean they want all nursing homes abolished. It means they wanted to offer a proper alternative for those people that would rather not stay in a nursing home. The projects are demand-oriented, starting from the strengths and possibilities of the persons with dementia. They are stimulated to use such possibilities to the fullest. Staff try to empathize with the inhabitants as much as they can, and to communicate from within that empathy. The participation of the inhabitants and of family members is crucial. The organization of care is subordinate to these principles and to the realization of a high quality of life for the residents.

Bulgaria – BU

Good practice

Support of Professional care workers: A positive and legally regulated practice is the additional paid annual leave to which family care service workers are entitled in their capacity of family care service employees. Employees in the *Shalom family care services*, besides this additional paid leave, also have free season tickets for public transport, regular medical check-ups and cash compensations for harmful labour, and some of them also have a business mobile phone. Nonetheless the care service sector remains poorly paid.

Summer holidays: Family carers are able to go on free or highly subsidised holidays with the person they care for in permanent camping sites.

Innovative practice

The day-care homes for the elderly are an innovative and highly effective practice to prevent older people from becoming socially isolated and enable the members of their family to work and be assured that the elderly people are under daily supervision and care.

Czech Republic – CZ

Good practice

Caring Municipalities: Some municipalities coordinate support services for their citizens and prepare information materials where caregivers can easily find out about alternative and available services. Good examples of "caring municipalities" are Chrudim, Litoměřice, Ústí nad Orlicí, Nasavrky, etc. Chrudim in the Eastern Bohemia Region of Pardubice and the Social Department of its Town Office provides a good example of systematic planning and development for a whole spectrum of necessary services for older persons as well as their caregivers. The planning of social services respects the needs of older people. All necessary services such as residential care, home assistance together with support and consultations for caregivers, printed information etc. are available from the municipality.

Some hospitals restructured their Long Term Care departments into modern geriatric centres that provide caregivers with support. The Geriatric Centre of the Regional Hospital Pardubice is a modern hospital department which integrates and coordinates care for seniors. The previous long-term care department was restructured in the early 90's into a complex acute geriatric department with rehabilitation and aftercare. Physicians of the Geriatric Centre provide geriatric consultations to other departments of the Regional Hospital Pardubice. They run an out-patient department dealing with acute and chronic geriatric problems and specialize in care for chronic wounds and ulcers, osteoporosis and metabolism. The Home care unit of the Centre provides home nursing care to patients who need skilled nursing care. Physicians of the Centre also consult general practitioners and other health and social care professionals including those from other home care agencies and residential homes. The Geriatric Centre is a teaching base for students of nursing, medicine and social work in undergraduate and postgraduate programmes. It is also an open institution and consultations and support for family caregivers form an important part of its activities. The idea behind the Centre and its organisation has been followed by others.

Gerontologické centrum v Praze 8, Kobylisích, the Centre of Gerontology, - is a community-based institution run by the Local Authority of Prague 8 District. It was founded in the early 90's as an integrated health and social care institution and offers a rehabilitation unit, a day care unit for patients with dementia, home nursing care, a social service department providing meals on wheels, a lunch club for seniors and consultations. The support and consultations to family caregivers are considered to be an important component of its activities. The Centre serves as a teaching base of social gerontology for students of the 1st and 2nd medical faculties of Charles University, students of social work, sociology, nursing, psychology, theology and others. Its research activities focus on the health and social care interface, quality of care in gerontology, social aspects and early diagnosis of dementia.

The Hospice movement in the Czech Republic started also in the early 90's. The first hospice was established in Eastern Bohemia. Now there are 6 hospices with 171 beds. Hospices provide palliative care for people in need; they support families during their relative's sickness and also provide them with support after bereavement.

Home services provided by NGOs such as Diakonie, Charita, Czech Red

Cross, as well as some municipalities, include both health and social care and therefore bridge the gap between health and social care. Some institutions were designed primarily to be open, integrated (health and social) and community based (Centre of Gerontology, Prague 8, Sue Ryder House, Prague 4 etc.).

Many **residential** houses transformed their "institutional" attitude into modern models open to a local community and providing modern services and care. Some residential type institutions established specialised departments of care for people with dementia. An important part of their activity is communication with family caregivers and their support.

Innovative practice

The **Czech Alzheimer Society**, founded in 1997, now has 30 contact and information points located in every region of the Czech Republic. Caregivers of people with dementia can get information and advice on dementia from these, as well as information brochures and leaflets. All information is available on the web pages of the Society which provide general information on various issues of dementia and a database of services for older people especially those affected with dementia. The Society organizes self-help support groups of family caregivers, counselling and respite care ("granny-sitting") for people with dementia. www.pecujici.cz (caregiver is pečující in Czech).

Farní Charita Karlovy Vary and Domov Důchodců Bystřany after a successful fundraising campaign established a **day care unit for people with dementia,** providing good quality care for people with dementia, together with support and respite for their caregivers.

Denmark – DK

Good Practice

There are three organisations in Denmark, which directly or indirectly work with and for relatives of dependent older people. The first one (Aeldremobiliseringen – Danish Association of Senior Citizens) is an umbrella association of local and regional older people's and pensioners' organisations. The second one (Aeldre Sagen – DaneAge Association) is a national (individual) member organisation working with and for older people. Both of these work indirectly with family carers in so far as they provide social support activities (for older people). The third organisation (Paaroerendegruppen for svage aeldre – National Association for Relatives of Dependent Older People) is a pressure group not working directly for family carers but for the dependent older people on behalf of their relatives. In all cases, the activities of the organisations in relation to

dependent older people coincide with national policy – it is to ensure that public services of the highest quality are provided to those in need when and where they need them.

However, one direct service developed by one of these organisations (DaneAge) provides **volunteer-based respite services** for families with an older person suffering from dementia. The organisation trains volunteers to be able to provide such services in the home.

There is also a wide variety of initiatives at the local level, which may be carried out by local groups of national voluntary organisations or may be carried out by purely local groups. These initiatives and the services provided are often publicly subsidized and carried out in close co-operation with local community services to support older dependent people. Such support may be provided in the home; may be provided in an institutional setting; or may be designed to help older people take part in activities outside the home.

The scheme run by DaneAge to **train volunteers** to provide support and breaks from caring for families with an older person suffering from dementia is one of the few (if not the only one) aimed specifically at supporting the family rather than the older person.

Finland – FI

Good practice

Four big associations The Association of Care giving Relatives and Friends, The Association for Old Age and Neighbour Service, The Central Union for the Welfare of the Aged and The Central Union for the Alzheimer Disease organize dozens of different projects per year together with local associations. The purpose of these projects is to support care giving families. Some of the projects are listed here. There are also many examples of innovative practices in support services.

VERROKKI - **Training peer group leaders for care groups** (2001-2004): The project was carried out in co-operation with 13 social associations. It is developing peer group activities in order to find new and promote old ways of providing emotional support for the family caregivers.

COMBINING WORK AND FAMILY CAREGIVING – *PROJECT* (2002- 2005): As the number of elderly people increases many working people will meet challenges when trying to combine work and caring for elderly parents. Working parents of handicapped children and spouse caregivers also share the same situation. The project is trying to find out good practices of supporting working family caregivers.

CHARITY COLLECTION TO THE CARE GIVERS 2001-2003 – In 2001 the Lutheran Church charity collection targeted 17.5% of its total collected funds for the Association of Care Giving Relatives and Friends. The project was called **"Best Carers"**. The theme of the charity collection in 2001 was "Take care of each other". The goal of this project was to raise awareness of the needs of carers at all levels (e.g. governmental and societal levels) and to ensure some action to support them. When helping the carers, the whole family becomes more aware of their roles, resources and status in their life situations. This project found caregivers who did not receive any support from parishes and regional associations. The project also arranged resource-weeks and 3-5 days´ courses specifically targeted at elderly caregivers and care recipients as well as families with

handicapped children. The project also collected information about the caregivers´ life situations and needs. Producing information materials and training were included in the project.

Associations of family care giving arrange for projects which are funded by Finland's **Slot Machine Association**. The purpose of the projects is mainly to support and help in the everyday life of the carer and the person cared for. As an example, the Association of Family Carers in the Jyväskylä district has implemented a project which aims at supporting the beginning of family care work. However, many times it is difficult to define the onset of caring work, because in reality it may have started long before a spouse has considered himself/herself as a family carer. In the same association a new project has recently been started with the aim of developing new ways of supporting family carers. One of the objectives of this project is to develop an **occupational health care** system for family carers to take care of their health and well-being.

Dementia associations also have different kinds of projects for demented people and their families, e.g. Southern Karelian Dementia Association had a project in 1996-1999 to study the effect of half-day help given in a dependent person's home by a personal home help/nurse. This project studied 168 families and family carers and reported that the project had helped their life and provided more time for themselves.

Innovative practice

In Helsinki, The Central Union for the Welfare has started a one-year study focusing on **personally tailored support for spouses as caregivers** for demented persons. In this study 128 families have been enrolled with one half of them comprising the control group. Families in the study group get a personal nurse who makes a support plan on the basis of the needs of this specific family. In addition family caregivers take part in a support group. The purpose of the project is to look at the effects of the support offered on the well-being of the family carer and the delay in the time before institutional care is needed for the demented person.

France – FR

Good practice

AIDANTS - Association française des aidants de personnes malades, dépendantes ou handicapées (www.aidants.org)– is an association of carers, created in December 2003, based on values of mutual aid with its objectives being the provision of information, support and advice, access to services and recognition by public authorities, professional carers and the public of the important role and work of informal carers. It aims at becoming a platform of information and advocacy for informal carers. AIDANTS edits a fortnightly Newsletter published on the Internet since December 2003 providing short informative articles on anything concerned with informal care-givers and the persons they care for (sick, handicapped and other dependent people of any age). The association also offers phone contact e.g. to inform carers on how and where to get help and support in their locality.

CLIC: Centre local d'information et de coordination gérontologique (Local centre for gerontological information and coordination) are local public agencies for information, advice, and orientation of the older population and their carers. Each agency has the same data bank and by

law fulfils the following tasks: evaluating the individual's needs, establishing an individual "help plan" together with the client, co-ordinating different services as part of the "help plan", development of inter-service collaboration, training of professional staff and systematic follow-up of each individual situation. Other important tasks are the provision of advice and support to informal carers, as well as the organisation of support groups for them. The agencies are mainly publicly funded (about 95%). By May 2004 only 413 agencies had been put into service; in six *départments* there is still none. Cost cutting has slowed down the development of the CLIC. Only cities with a well established socio-gerontological policy and real concerns for older people's situation created CLICs and provide them with adequate financing.

Fondation Médéric Alzheimer (*http://www.fondation-mederic-alzheimer.org*): created in 1999 by Médéric, the oldest caisse de retraite complémentaire (pension supplementary fund), it was endowed with 76,225 million €, with a yearly budget of about 2.3 million € and thus could play an active role concerning dementia in old age and family carers. The foundation cooperates with associations and political authorities that develop initiatives and programmes to support family carers. It identifies the needs, encourages innovative initiatives and provides information on good practice. It distributes information on dementia in old age from specialists and organisations to professionals, individuals and the media. Thanks to its publications and press reviews it sensitises a wide public. Workshops are organized with specialists to discuss and gather information on special subjects (e.g. support groups for carers). The foundation finances social research, as well as local initiatives. By September 2003, 92 projects had been supported. Projects are selected through a call to tender and support is not only financial, but also helps to the team during the development period.

Cantou[3] *Centre d'Activités Naturelles Tirées d'Occupations Utiles* (Centre of natural activities linked to useful work) (Phone: + 33 (0)1 47 49 44 08 FAX: + 33 (0)1 47 32 23 99). *Cantou* is a special housing and care concept for older people suffering from dementia. Created in the early seventies by the director of a traditional home for older people, who was confronted by the increasing number of his residents who had lost their intellectual capacities and who was unwilling for them to move into nursing homes (providing inadequate social care at that time), he founded the *Cantou*. Initially he changed one floor, but over the years, with the success of the concept for the residents, their family, and this type of patient, all seven floors were altered. The model is in continuous development to improve daily life and working conditions, to adapt to new needs, to take into account the wishes of the family and is the result of regular quality evaluation.

Twelve persons live together; each with their own room with bathroom and WC; they move in with their personal furniture and decoration. The residents share their daily life in a spacious room with a big table and the kitchen in the middle. Their main occupation is cooking together for lunch and dinner. A professional housewife has the key position, supported by nurses, night carers, cleaners etc.

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[3] This complicated name is based on the fact that *Cantou* in the langue d'Oc (group of southern French medieval dialects) is the huge central fireplace in the farm where people come together. The creator of the *Cantou* is originally from this region.

Unlike traditional homes for older people, the *Cantou* does not take over moral responsibility for the resident, which remains in the hands of the family. The family has the key position at the level of decision making: all important decisions are taken by the families in monthly meetings. According to the director's definition, the *Cantou* is release care for the family and excludes the family's resignation.

The family is integrated in the social life of the *Cantou* and invited to spend as much time as possible within the group, participating in and offering any kind of indoor and outdoor activities. A main advantage is that the family member (very often the former main carer) no longer has to endure the unsupportable face-to-face confrontation with the demented mother, father, husband or wife. This does not mean that the family member cannot withdraw together with his relative into his/her room or go out alone for a walk. Many family members are so integrated that after the death of their relative they carry on with their habit of spending time in the *Cantou*.

In case of acute illness, the resident can be hospitalised, but the director of the *Cantou* is still concerned to get them "home" as soon as possible. Residents die in the *Cantou*: the staff is trained for such care and the family is invited to assist them (and *vice-versa*); if wanted, relatives can stay over night for as long as they want, until the death of the resident.

Staff and family members are followed up by a psychologist who has been directly involved in the concept and development of the *Cantou.* Analogous experiences exist, but in general, the family is less responsible and less integrated and the residents not involved in the preparation of the food and cooking.

JALMALV - Jusqu'à la mort accompagner la vie (Accompanying life until death). This movement is devoted to accompanying dying persons, based on experiences from Anglo-Saxon countries. Created in 1983 in Grenoble, by 2004 it consisted of 61 local associations, federated at regional and national level. It is a founder member and administrator of the European association EAPC and the French SFAP[4]. Since 1985 JALMALV edits a quarterly Revue *Jalmalv* giving information and reflections on accompanying and palliative care. The objectives of the association are to accompany dying persons of any age, wherever they are (at home, in a hospital or any other institution); to contribute to changing attitudes towards the dying; to support formal and informal carers using volunteers; support the bereaved; promote the development of palliative care; and promote research on the physical, psychological, social, and spiritual needs of older people at the end of life.

To reach its objectives, four basic activities are involved: consciousness-raising (conferences, public debates, information meetings, dissemination of brochures, books, reviews, etc.); press conferences; accompanying and support; training; research. http://www.jalmalv.org/

Accueil familial is private accommodation and care, regulated by law (1989) to prevent abuse and protect the cared-for persons. A family, or a person living alone, offer paid accommodation and care to up to a maximum of three persons, aged ≥60 years or to an adult with mental/physical disablement aged >18 years. Temporary accommodation and care is authorized,

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4 Société française d'accompagnement et de soins palliatifs

thus offering places to dependent older people while their family carer goes on holiday, is ill, etc. *Accueil familial* requires an agreement with the local authority (*Conseil général*), given under the following conditions:

- signature of an official contract between the hosting and the hosted person (form edited by the local authority); the contract has to be confirmed yearly
- offer of a single room inside the house of the host, minimum 9 m^2 (16 m^2 for a couple) and individual or familial toilets and bathroom
- guarantee of housing comfort and hygiene
- guarantee of security and safety of the hosted person and her goods, as well as of her well-being
- acceptance of regular social and socio-medical follow-up and regular control.

The hosting person must get a monthly payslip, pay the same social contributions as any employee, and is legally entitled to holiday. The income has to be declared to the fiscal administration. The remuneration is determined by the local authority. Example of one *département*: basic gross salary: 564 to 715 €/month, plus an indemnity of 265 to 442 €/month for caring (according to the degree of dependency), plus a rent 150 to 180 €/month. [Conseil Général Saône-et-Loire]

A priori the hosted person cannot be a family member, but due to the national dependency insurance (APA) this has changed: the hosted person can benefit from APA, and can chose the carer he/she wants to remunerate for caring (spouse excluded), and that can be done under an *Accueil familial* contract. Family carers rarely think about this possibility, generally they do not know that it exists, and the steps are complicated for them. The advantage for the family carer is the guarantee to be paid and to be legally entitled to holidays; the advantage for the cared-for relative is the guarantee of quality control. There might be a snag: the initial law excludes the hosting person from inheritance and it is not clear if this alters when the hosting person is a relative.

Accueil familial has been particularly developed in villages, too small to build up a home for their older people but wanting to maintain them within the village. The mayor of one small village with 400 inhabitants created a special form: he built up two adjoining, identical houses communicating on the ground floor. Each house is divided in two parts: a flat on the first floor for the hosting family; three rooms, one bathroom, a kitchen, a living dining room on the ground floor for the hosted persons. The two hosting families are supposed to complement each other (e.g. watch-over when one of them is out.) There are two national federations[5] of the *Accueil familial*. Several local authorities are opposed to *Accueil familial* and tend to impede it: they invest in traditional homes for older people or already subsidize them and want them to be fully used.

Innovative practices

The municipality of the City of Paris has instituted the **"Prize for good treatment"** in socio-gerontological sports and culture. In 2004, the section "Taï Chi Chuan" of the public hospital Bretonneau won the prize. Family carers are invited to join the weekly group for discussions.

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[5] FNAF – Fédération Nationale de l'Accueil Familial. FAMIDAC – Familles d'accueil et leurs partenaires

Valuable information on the Internet, helpful to carers and older people, is produced by associations specialised in community care, residential care, in gathering information, and on special health issues (e.g. osteoporosis, incontinence).

Germany – DE

Good practice

In the different federal states there are many model projects with various foci and aims. They all aim to promote the transparency of the social and health services by building up networks and supporting cooperation between the different services offered, especially between the in-patient and out-patient care sector. The relevant subsystems should then be able to tailor their benefits more fittingly to the needs of family carers and persons in need of care. A solid cross-section (N = 58) of innovative and good practices aimed at improving the quality of life of older people in Germany have been gathered through the research project ProNetz and their innovative elements described. Nearly all projects have integrated the support of family carers, by providing information and advice, training, measures to relieve the burden of care or weekend breaks for family carers and the older person suffering from dementia.

The "Network for the Aged" (Netzwerk im Alter) was founded by the organization "Albatros" in Berlin-Pankow (Berlin) in order to promote cooperation between all institutions concerned with the provision of care for older people. A binding case management and transition system and qualification programmes for networking were developed and tested. In addition relatives were qualified and a complaints management office was started. This network made the social services more transparent to family carers and improved their consumer competencies.

The Network for Geriatric Rehabilitation (GeReNet.Wi) in Wiesbaden (Hessen) concentrates on problems which arise in the context of intersecting areas between old age care institutions and the health care system. A training course which qualifies people as "voluntary senior citizens companions" is offered by the Department for Social Work in Wiesbaden, with the intention of lessening the burden of care and giving support to family carers. The main focus of this service is on voluntary work and the psychosocial assistance of family carers who need a few hours of free time.

The project "Fourth Phase of Life" in Stuttgart (Baden-Wuerttemberg) and "KUNZ" which is a church neighbourhood centre set up by a parish in Bielefeld (Northrhine Westfalia), also put into practice the idea of voluntary helpers and community centres. In addition to the reduction of strain on family carers through voluntary helpers, a main aspect of these projects is the development and promotion of services for older people living alone which cater to their specific needs.

The project "HALMA" e.V. in Würzburg (Bavaria) offers support for cognitively impaired people by arranging volunteers to relieve family carers for some hours.

The project "GeNA" - a geronto-psychiatric network of family carers in Neustrelitz (Mecklenburg - Western Pomerania) focuses on building up networks of existing services to support family carers and to look for needs-orientated services.

Caregiving courses are also offered to a target group of **migrant caregivers**: for example a course in Wiesbaden offered to Turkish migrants in the Turkish and German languages, a future-orientated service which is tailored to fit the needs of the growing group of migrant carers (www.seniorennet.de). Another project tailored for elderly chronically ill migrants and their family carers is carried out by two charitable organisations in Berlin: Arbeiterwohlfahrt – AWO - and Caritas.

Furthermore the Federation of Advice Centres for Older People and Family Carers – BAGA - has published **a manual for professionals** on how to give advice and support to family carers of older people suffering from dementia. This manual incorporates best practice and innovative projects focussed on groups for family carers, practical training and support groups for older people suffering from dementia, advice and counselling in domestic care environment, volunteer services, cafés for family carers and Alzheimer-dancing-cafés. The manual is completed by comprehensive information related to family caring and the relevant legislation.

Innovative practice

In Germany innovative practices in support services are based on building up **networked structures** and working with elements of cooperation and coordination on both personal and institutional levels. In the research project ProNetz, three basic categories of approaches for network activities as well as elements to avoid or improve networking activities were identified:

1. community-based networking
2. networking orientated towards institutions
3. networking orientated towards target groups

Factors that improve networking at a structural level include the availability of a designated centre (office, café, seminar-room); a virtual centre (Website, events, flyer, documents, and a "personal" centre (such as a network manager/care manager, clerical secretary).

Factors which improve networking at a procedural level include the definition of aims;

contracts; responsibilities carried out permanently and reliably; the process of networking being accompanied by an external moderator; further education across all professional groups ; reimbursement.

Factors obstructing the process of networking include a lack of financial support; high staff turnover; excessive competition between the institutions; a lack of support from the service purchaser or chair; confusion about areas of responsibility between insurance companies and municipalities.

This summary from the research project ProNetz can help staff in social and health care provision or in health or long-term care insurance companies to identify innovative care concepts and models, in order to give incentives, examples or support in planning their own networking activities and to help sponsors in decision making towards the provision of financial subsidies

Greece – EL

Good Practice

GARDA: The Greek Alzheimer and Related Disorders Association is an innovative attempt to help those with Alzheimer and their carers; it has become a 'state of the art' model for the integration of care services in Greece. Established in Thessaloniki in 1995, as a non-profit, non-governmental organization, its purpose is to optimize the quality of care for AD people and their carers. The Greek organization was initiated by the International Alzheimer Association in conjunction with the current President of GARDA, and Alzheimer Disease International (ADI) provided help in developing skills for setting up the Association, identifying aims, fundraising, recruiting volunteers, running support groups, raising awareness and providing information. In 1997 GARDA became a member of Alzheimer Europe and in 1998 expanded and created branches in five other cities (Athens, Xanthi, Volos, Chania, Larissa).

The core of the foundation is a large team of volunteers from various fields such as physicians (mostly neurologists), psychologists, physiotherapists, social workers and others. GARDA promotes its fundamental aims through a wide range of activities including comprehensive and accurate information on all forms of dementia, on caring, legal and financial matters, social and health services and benefits; a network of carers groups, carers contacts and a telephone helpline; its own magazine; regular courses, meetings and conferences.

It also delivers quality day care through 3 day-centers, offering discussion groups, seminars for caregivers and professionals, memory training for patients presenting with early-stage disease, music therapy for patients at all stages, speech therapy and physiotherapy. One of GARDA's objectives is to raise money in order to build a Clinic where patients in the late stages of AD will get the care they need and it recently obtained some financial support from the Ministry of Culture for this.

GARDA promotes research, education and training and a large number of AD patients and their carers take part in research activities (validation of neuropsychiatric scales, genetic research, and new pharmacotherapeutic trials, epidemiological aspects in Greece, prevalence, incidence, outcome and institutionalization). http://www.alzheimer-hellas.gr/

Evaluation of the "HELP-AT-HOME" SERVICE

Planning and evaluation: Local Authorities in Greece began home care services, mainly during the past decade. 97 of these were evaluated in a pilot programme covering their first 3 years' of operation. Evaluation is rare in the Greek context but the results from the 400 Municipalities currently operating Home Care Units (100 Help-at-Home and 300 Social Care Units) are to be used as a basis for funding and planning for the 1100 Municipalities in Greece.

Financial evaluation indicated that one Help at Home programme with 3 employees, operating from a local Open Care Community Centre for Older people (KAPI) and providing full support at home for 60 dependent older people, cost 35216 euros per year in contrast to 17608 euros per year for institutional/residential care per older person. i.e. the equivalent of supporting 30 dependent older people at home.

The use of volunteers is important in these programmes, besides the professional staff, and help is needed in devising more efficient and effective strategies for the management of volunteer services. The development of additional methods of support to cover the needs of older people (Day Centres for social and nursing care, respite care, mobile care units, long-term social and nursing care centres and centres for the care of active dementia sufferers) are also needed.

The long term funding of these programmes is insecure.

Hungary – HU

Good practice

Integrated Care: in order to solve the problem arising from the separation of health and social care, in 1992 the state authorised the Budapest Centre of the Hungarian Maltese Charity Service to establish a secondary school where students receive a qualification both as social workers and assistant nurses. After leaving school they are able to work in both areas. It linked two year health and social training and also created jobs for disadvantaged young girls and boys living in poor family circumstances with emotional and family deprivation. After finishing their studies the young people took jobs in care for the elderly where, besides carrying out care and nursing tasks, they also functioned as quasi-grandchildren. After a while they regarded the paid work as a family task and the elderly persons treated them as grandchildren (elderly women baked cakes for them, etc.). With this the organisation introduced several innovations simultaneously: it linked health and social training; created jobs for disadvantaged young girls and boys living in poor family circumstances with emotional and family deprivation; at the same time it gave both the young people and the elderly a "family" background, a quasi family; and finally it combined all this with a new kind of high technology, the alarm bell system. It developed a technology for this that took Hungarian characteristics into account, in particular the fact that many elderly people do not have a phone. Thus they carried out social, health and technological innovations simultaneously. In disseminating the model throughout the country they developed a number of sub-models taking into account the characteristics of the given region, settlement and housing structure and since it was aimed principally at the poorest strata – the service was provided free of charge – with this care type the organisation found what can be considered a path out of the poverty trap. As a by-product of the model "informal helping sub-types" arose in many settlements, e.g. alarm units were made by neighbours connecting an elderly person to their home.

Innovative practice

The *Elderly-friendly housing program* helps safe living at home for elderly people by altering the apartments of elderly persons with loss of functions to ensure greater accessibility. It is vitally important to prevent falls. An investigation conducted prior to the alteration in a country town and a district of Budapest found that around half of the elderly persons living at home and in need of care have falls and around one fifth of the falls are caused by unsuitable conditions in the apartment. Numerous apartments have already been altered.

Interestingly, it was much more difficult to introduce the service among persons cared for by someone being paid a "nursing fee for a family member" because of the resistance of family

members, who did not want to accept any kind of help. There may be a number of reasons for this; they may be afraid that the elderly person will gain greater autonomy and so become less dependent on them and they may also lose their small income; they fear that the appearance of the state and the civil organisation will in some way endanger their inheritance; they are afraid of exposing the elderly person to the increasingly widespread abuse and robbery.

Ireland – IE

Good practice

The Carers' Charter was compiled by Professor Joyce O'Connor, Director National College of Industrial Relations, in association with Soroptimist International, Republic of Ireland National Project "Caring for the Carers" and with the help and support of carers and groups working with carers. It is often used as a reference point today. The work of *Caring for Carers Ireland* has been governed by the principles of the Carers' Charter.

The Carers' Charter is as follows:

1. Carers have the right to be recognised for the central role which they play in community care and in creating a community of caring.
2. Carers have the right to acknowledgement and address their own needs for personal fulfilment.
3. Carers have the right to practical help in carrying out the tasks of care-giving, including domestic help, home adaptations, appliances, incontinence services and help with transport
4. Carers have the right to support services, e.g. public health nurses, day centres and home helps in providing medical, personal and domestic care
5. Carers have the right to respite care both for short spells as in day hospitals and for longer periods to enable them to have time for themselves
6. Carers have the right to emotional and moral support
7. Carers have the right to financial support and recompense which does not preclude carers taking employment or in sharing care with other people
8. Carers have the right to regular assessment and review of their needs and those of people for whom they care
9. Carers have the right to easy access to information and advice
10. Carers have the right to expect involvement of all family members
11. Carers have the right to have counselling made available to them at different stages of the caring process including bereavement counselling
12. Carers have the right to skill's training and development of their potential
13. Carers have the right to expect their families, public authorities and community members to provide a plan for services and support for carers, taking into account the unique demographic developments up to and beyond the year 2000
14. Carers have the right to involvement at all levels of policy planning, to participate and contribute to the planning of an integrated and coordinated service for carers
15. Carers have the right to an infrastructure of care, a supportive network to which they can relate when the need arises.

Carers Clinic

Caring for Carers in partnership with the Mid Western Health Board established a Carers Clinic to meet the needs of Family Carers of Older People who are themselves Carers, to address isola-

tion and to promote social inclusion. Following a **Needs Assessment** the Clinic develops **integrated packages** of care for Family Carers.

Respite Care Programme

Family Carers who would otherwise not have a break from their 24 hour day caring roll have benefited from the *Caring for Carers Ireland* programme which includes an annual National Respite Break and Conference. This provides a forum and platform for Family Carers. To date 8,000 have been facilitated with in-home respite and week-end breaks.

Patient Discharge Summary

Through partnership with Hospital and Community Service Providers, *Caring for Carers* have compiled a Patient Discharge Summary to provide information to patients and their Carers to promote the safe transfer of Care from Hospital to home.

eHealth Project

One of the biggest challenges facing older people and those they care for is a sense of isolation and social exclusion. To help overcome this *Caring for Carers* in partnership with Comhairle, Mid Western Health Board, Ennis Citizens Information Centre and Ennis Information Age Town established a Programme using Information Technology to improve access to information, advise and advocacy on a broad range of health and social services for a target group of over 1,500. The Carer's Centre acts as a hub linking together 5 Day Centres through use of web cam. Carers now can access a wide range of services without having to leave their local area. On-going training ensures Carers take advantage of new technology. *Caring for Carers* were finalists in the eHealth Europe Awards 2004.

Personal Security Systems: Security devices are provided by *Caring for Carers* to vulnerable older people in the community to promote safety and security in the home.

Carers Benefit and Carers Leave: Although there are many problems with the Irish approach to supporting carers and those that they care for, there has been increasing recognition of the need to support carers to take time out from working to care for a dependant person. A right to do this was introduced with the Carers Leave legislation and a certain level of social insurance based income support is provided through Carers Benefit.

Equality legislation: Ireland may be unique in the referencing of carers in its equality legislation – the Employment Equality Act (1998) and Equal Status Act (2000). The equality agenda for carers is currently being elaborated by the statutory equality agency – the Equality Authority.

Caring for Carers Ireland: A national non-governmental organisation with a growing network of 55 Carers Groups North and South. *Caring for Carers* aims to promote the health, wellbeing and quality of life of Family Carers and those for whom they care. They also promote recognition, providing information, training, respite care and advocacy to promote social inclusion within the context of the carers' charter.

Services Provided: *Caring for Carers Ireland* has developed a network of Carers Groups, Carers Clinics, Training Programmes for Family Carers, Respite Care and Information, National Respite Weekend and Conferences, Health Promotion and eHealth Programme. The Carers Association

provides home respite services, training, information, support and counselling, advocacy, information packs and lobby the government. It operates from carers' resource centres nationally. Establishment of Carers Groups; Carers Clinic; Training Programmes for Family Carers; Respite Care and Information; National Respite Weekend and Conference and Information days; eHealth Programme.

The Carers Association is a national voluntary organisation representing family carers in the home who provide fulltime care for a family member who may have a disability. It provides home respite services, training, information, support and counselling, advocacy, information packs and lobbies the government. It operates from 16 carers' resource centres nationally and employs over 180 people.

Services Provided: Home respite; training; information; advice; support; counselling; support groups; carers resource centres and outreach centres.

The Alzheimer Society of Ireland' s mission is to work for and on behalf of people with dementia and their carers and ensure they have the necessary supports and services to enable them to maximise quality of life, respecting the needs, rights and dignity of the individual. Services provided include: practical information and emotional support through help lines; provision of literature; day care and respite; home support and support groups.

Carers Support Programme – CROSSCARE aims to improve the quality of life of family carers who are often vulnerable and under considerable stress, mainly in the Dublin area. The aim is achieved by offering support in the form of information, knowledge, practical skills, counselling, personal development and group support to the carer, phone support, respite breaks for carers, bereavement support for carers.

CROSSCARE believes that if the carer is appropriately supported, not only will the well being of the carer improve but it may also enable the cared-for person to remain in the family home and in the local community, thereby avoiding the prospect of long term institutional care. Support group meetings are held monthly.

Caring and Sharing Association is a voluntary group which develops friendships through a variety of activities such as Lourdes Pilgrimages, respite breaks and local social groups. It provides the following services mainly in Greater Dublin, Cork City and County Longford: respite breaks and social services; pilgrimages to Lourdes with full palliative care (medical, spiritual and companionship); training and support for carers.

Italy – IT

Good practice

The practices described are more common in the northern and central regions of Italy than in the South of the country.

In the territory of San Donato Municipality, near Milan, the social cooperative "Solidarietà e progresso" (Solidarity and Progress) has realized a project named "Support Services for caregivers", presented in 2001 on the basis of the regional Law 23 / 1999 "Regional policies for the family".

The service was free, it was implemented for one year and the project was elaborated so as to integrate socio-sanitary services already existing in the territory. The service aims at providing carers with forms of support such as information service, counselling and advice, and first assessments of the project seem to be positive about it's impact on well-being of caregivers.

Another interesting form of experimentation called **"Parente-sì"** has been carried out in the ASL of the province of Milan 2. Its focus was on the re-appropriation of "time for oneself" on the part of carers of non self-sufficient elderly people assisted at home. The experiment, that lasted 6 months and involved 20 families that received support for 4 hours a week with the participation of several social operators, has showed how difficult it is for the carers to leave the isolation in which their caregiving tasks have confined them. This finding has implications for the need for projects that can guarantee continuity of care to the assisted person and help and counselling to the carer.

In one ASL in Rome an **experience of home care services for demented elderly persons** was carried out, centred on a complex network of services: Geriatric Day Hospital, Community Care Centre, ADI, RSA, groups of help for carers, a telephone line for carers' information and training and courses for home carers in order to alleviate caregivers' stress.

In several parts of Italy, **groups of mutual help for people who lost one of their relatives** have grown and become a very important social resource since professional people and social services are not always able to respond to the complex needs linked to death.

Innovative practice

The new role of "**health and social guardian**" (custode socio-sanitario) has recently been introduced by the Milan Municipality, with the function of identifying the needs of elderly people in difficulty, through their daily contact with those living in a specific district, and acting as timely initiators of the necessary interventions by public and private service deliverers, voluntary worker associations, parishes and any other relevant social resources available locally
www.centromaderna.it/anziani/newsletter.asp

The relevance of such an initiative is further enhanced by the fact of its linking up with another project of great socio-medical relevance: the "**counselling bureau for the elderly**" (sportello unico per l'anziano), implemented with the aim of taking charge of situations which place elderly people at risk, and supporting caregivers in their problem-solving difficulties throughout their caring. On the basis of this first experimental project, the idea is currently being implemented also at the national level by the Italian Ministry of Health.

www.governo.it/GovernoInforma/ Dossier/anziani_caldo/caratteristiche.html

In another Municipality in Northern Italy, Modena, a **counselling service for carers of older people being discharged from hospital** has been recently implemented. Currently this centre, which cooperates within the Specialist School in Community Medicine of the University of Modena and Reggio Emilia, is still operating only a few hours per week, providing mainly a guidance service, but its long-term aim is to strengthen all kinds of support to carers, according to the critical needs mentioned by carers themselves.

The Florence Municipality, with the legal advice of **Studio Come** has implemented a project called "Older Adults at Home" (Anziani a Casa) with the aim of overcoming the separation between the private services "market" (based upon family responsibility and usually devoid of security) and the public sector provision (reserved mainly for the minority of citizens belonging to the lower income brackets). The novelty of this project in comparison to similar current experiments e.g. those implemented within the context of the SERDOM project, located in the Northern Italy cities such as Modena, Parma and Turin www.comune.modena.it/serdom/ sito/stampa.htm, lies in the fact that Florence is the first Municipality to respond to the need to offer both financial support and security, while establishing also a community information service for family caregivers and local solidarity networks.

The project **Intensive Care,** is an initiative of free home care for families that have a relative affected by Alzheimer's disease and who live in Milan (the initiative is promoted by Fondazione Manuli) and it aims at giving respite care 4 hours a day for 5 days a week during a year. This project can be considered innovative both for its means and its modalities, since it offers the carer the optimisation of his/her own personal resources and promotes a **continuum** of caregiving, information and support to the family

Another innovative project, implemented in the European context, is the **Progetto CRONOS,** addressed to persons with **Alzheimer's disease**, their families and all the specialists involved in this issue. The most noteworthy feature is the Internet website entirely devoted to the project, that the Ministery of Health has set up at a national level. Besides providing information on the disease, the site also offers a possibility of discussion and confrontation between doctors, families and care providers, and useful information for carers in finding their way among the various services: the site offers also a list of Assessment Units and working Centres involved in the project, throughout the whole Country (http://212.38.48.166/main.htm). However, the project was funded only until the end of 2003, so that despite its positive results there is uncertainty about its future development.

Luxembourg – LU

Good practice

Two foundations – "**Hëllef Doheem**" (Help at home) and "**HELP**" – are in charge of providing aids and services to dependent persons; both are foundations for public utility and represent federations of several charitable and catholic institutions active in the field of care before the implementation of the dependency insurance. Both institutions work in close cooperation with the Ministry of Social Security and the Ministry of Family Affairs.

The foundation "**Hëllef Doheem**" represents the association of three former foundations:

"*Aide Familiale Aide Senior*" (Help for Families and Seniors) founded by the Caritas of Luxembourg at the beginning of the 50´s for the support of families in case of illness or absence of the mother, enlarged its services for older people during the 80´s;

"*Foyers Seniors*" (Community Centres for Seniors) consists of three community centres for older people founded in the 80s which offer several services (meals on wheels, activities, etc.) for older people;

"*Hëllef Doheem Krankefleg*" (Help at home nursing) was founded in the beginning of the 80´s by seven religious congregations in Luxembourg providing care at home.[6]

The aim of the network "Hëllef Doheem" is to care for all children, adolescents, adults, and older people in need of support and ambulatory care, especially those with physical diseases, handicap and/or dependancy who have temporary or chronic difficulties which cannot be compensated for by the family and which put the autonomy and living at home of the concerned person at risk. Help provided by this institution also addresses persons who live alone, as a couple or as a family in apartments adapted for older people. There is no discrimination on the basis of philosophical, theological, and religious or ethic beliefs. "Hëllef Doheem" offers its help and care services in the seven regions of the country (North, East, West, Centre, City of Luxembourg and surroundings, South), which guarantees a high proximity to the persons in need.

Coordinating services represents a central feature of the network. A coordinator is appointed for each client, in charge of informing the client and his/her family about help care services he/she may profit from, the initiation and organization of necessary services, and the observation and evaluation of the state of health and/or dependency in order to adjust the services.

The foundation has created an info line, available to anyone in need of information about the network and its services, dependency insurance, and the potential measures to be taken to assist living at home. The personnel structure of the network is multidisciplinary and comprises 25 teams of 7 to 12 professionals across the country under the supervision of a coordinator; each team is composed of nurses, nursing aids, family as well as home helpers; the total of personnel amounts to 1,100 persons. For specific tasks each team can rely on the services of occupational therapists, social assistants, physiotherapists, or psychiatric nurses.

The services of the network vary. For those covered by the dependency insurance, there is support with daily activities and routines (i.e., hygiene, mobility, nutrition), domestic tasks (i.e., washing, shopping, cleaning), individual support activities as well as counseling. Each nursing service is covered by the national health assurance (i.e., injections, infusions, taking blood samples, bandage and bonds, surveillance and posing of tubes and catheters; control of diabetes). There is immediate help after a hospital stay, or in case of illness or temporary incapacity due to an accident; provision of temporary personnel for assistance and surveillance if a caregiver is in need; various community centres ("foyer de jour") with leisure time activities, contact and communication facilities, as well as food provision; 24h Tele-alarm providing instant help in case of acute problems; assistance, counselling and orientation of relatives in charge of a dependent person; procurement of a temporary stay in a nursing home.

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[6] Congrégation des Frères de Charité, Congrégation des Sœurs du Tiers-Ordre Régulier de Notre-Dame du Mont Carmel, Chanoinesses régulières de Saint Augustin de la Congrégation de Notre-Dame, Congrégation des Sœurs de la Doctrine Chrétienne, Congrégation des Franciscaines de la Miséricorde, Congrégation des Sœurs du Pauvre Enfant Jésu, Congrégation des Sœurs Hospitalières de Sainte Elisabeth.

The second charitable organisation "HELP" consists of four organisations and institutions and is in charge of domiciliary care and aids. These consist of three residential homes for older people and their associated community centres in the north, south, and east of the country (Homes "Syrdall", "Uelzecht", and "Musellheem) as well as the service "Dohéem versuergt" (Help at home) provided by the Luxembourg Red Cross. HELP offers a list of services comparable to those already described for "Hëllef Doheem", which are covered financially by the national health insurance and the dependency insurance.

The service approach of "HELP" can be described by its systemic and patient-centred approach realized by a multidisciplinary team. Special emphasis is given to the prevention of dependency both for physical and psychosocial risks such as solitude and isolation. "Dohéem versuergt", the comparatively largest part of this network, has created since its coordination with "HELP" in 2001 approximately 240 places of work for employees, who are in charge of domiciliary aid and care. The multidisciplinary personnel includes nurses, nursing aids, family and home helps, physiotherapists, psychologists, and occupational therapists with a clear weight on the first three professional groups. The service has 14 help centres across Luxembourg covering. The three residential institutions provide similar services in close cooperation with hospitals and provide work for 250 persons.

Overall the provision of services for care at home seems to be quite sufficient in Luxembourg, since the two networks "Hëllef Doheem" and "Help" cover the whole of the country and employ approximately 1,600 persons of various qualification and training in the sector of home care. This may explain why there are no private care services in Luxembourg.

Challenges, which both organisations will have to face in the years to come, is quality evaluation with respect to structure, services and aids (which is currently realized for "Hëllef Doheem"), the elaboration of services especially with respect to palliative care, as well as a continuous training of their personnel.

Malta – MT

Good practice

Caritas – Malta is the main source of voluntary action in the field of aging. It gives two kinds of support to carers of elderly persons, namely information and training. Caritas informs the carers about the existence and availability of services for older people being provided by the State, the Church, other voluntary organisations and the private sector. Caritas has since 1996 been organizing training programmes for family carers who care for an elderly relative at home. Guided by the Christian outlook on care giving, Caritas firmly believes that the place of older people is in the family and, therefore, family carers need help from specific programmes which will enable them to give real and effective support to their elderly relatives. All "Care for Carers" programmes are open to all carers and consists of nine sessions aimed at supporting the carers by helping them to reduce stressful situations, improve communications, provide care in a more effective and efficient manner, etc. Themes covered include: communication skills; stress and strain management; time management; dealing with guilt feelings. Through group workshops there are opportunities for carers to exchange experiences and discuss the management of prob-

lem behaviour and difficulties; allows relatives to express feelings of sorrow, guilt and anger; offers self-help; supplies information and advice. These training programmes have been effective in terms of emotional support provided to and by carers.

Cana Movement (another Church organisation) also supports informal carers of elderly relatives through the running of monthly training programmes similarly called "Care for Carers". The topics dealt with include, solitude and loneliness; first aid; spirituality; technical aids and equipment; need of communication between the carer and the older person being cared for and also how this can be effected; personal hygiene; existing services for older persons and how to make use of them; caring for demented persons and for those who are mentally disabled.

Malta Memorial District Nursing Association (M.M.D.N.A.) supports family carers by offering nursing care to their frail elderly relatives. Under contract with the Health Division of the government of Malta, this non-governmental nursing association is responsible for coordinating all government domiciliary general nursing services throughout Malta. Members as individuals or groups currently pay low amounts that cover nursing visits and the provision of nursing products for the member, his wife or her husband as well as other persons dependent on the member and sharing the same residence. In 2002, the Association had 1,955 individual members and 18,190 group members. During 2003, 13,594 visits were made to these members by the nursing staff complement made up of 20 full time and 4 part-time state registered nurses, 9 full-time and 5 part-time state enrolled nurses. This staff averaged 37.2 visits a day.

During 2003, the total number of visits carried out under contract with the government was 372,422. This means that an average of 1,020 visits was carried out daily. There is a staff complement of 60, the majority of whom are qualified nurses, with older people forming the majority of the patients visited. During 2003, older people took up 86.7 percent of all the services offered by MMDNA during that year.

The Malta Hospice Movement is a private voluntary organization, inspired by Christian values, that provides and promotes the highest possible standards of palliative care for persons with cancer or motor neurone disease and helps and supports their families. The aim of the Movement, founded in 1989, is to enhance the patients' well-being and quality of life, to help them live as fully as possible until they die and to support their families during this difficult time.

During the past 15 years, the Movement has developed the following services which can be classified into 5 main categories: 1) Home Care which includes respite nursing, physiotherapy, hydrotherapy, occupational therapy, complementary therapies, psycho-social and spiritual support; 2) Day Therapy, which includes regular nursing assessment, assisted bathing, salon services, and divisional therapy; 3) Hospital Support; 4) Loan of Specialised Equipment; and 5) Bereavement Support.

The services are delivered by fully qualified professional staff and are complemented by dedicated and trained volunteers. These services are provided free of charge. Although cancer occurs at all ages, statistics issued by the Department of Health, show that the incidence of cancer is more prevalent among older people. During 2003, 328 patients were newly referred to the Hospice and 74% (242 patients) were over 60 years of age while more than 50% of the remaining 26% were in their late 50s. (Malta Hospice Movement, 2004) Other activities include the

loan of specialised equipment to facilitate home care and to enhance the quality of life both of the patient and also of the family e.g. special beds, hoists, commodes, wheelchairs, etc.

Bereavement Support aims at supporting families during the crucial time of grief following the loss of a loved one. This support to the family is continued for as long as necessary or as required. Relatives are invited to a memorial mass on two or three occasions after death. One to one and/or group support for the bereaved is very much appreciated by the relatives.

The Netherlands – NL

Good practice

The Guest House Amsterdam (Het Logeerhuis Amsterdam) is part of a large organisation for intramural health care (Fontis), with different nursing homes and residential homes in Amsterdam. The aim of the guesthouse is to relieve the direct environment (i.e. the informal caregivers) of community-dwelling demented elderly. The organisation has a service and hotel function. Guests receive care 24 hours per day and different activities are organised for the demented older people. Informal caregivers are able to go on holidays, have time to take a break etc.

There is room for 12 guests and also for 10 day guests and they can stay for a maximum of three to four weeks. Older people who have been discharged from hospital, but who need extra care can stay for a maximum of six weeks.

The criterion for a stay is that the older person has to have a diagnosis of early dementia. Older people in a severe state of dementia are not able to stay. Informal caregivers are mainly referred to this guesthouse by social workers, GPs and formal home care services. The guesthouse is an AWBZ-institution. Guests have to make a co-payment. The factors in their success are flexibility (short intake procedure, diversity in lengths of stay), domestic sphere and hospitality (the guesthouse has volunteers hostesses), the good contact of informal caregivers and personnel who provide information and emotional support.

Innovative practices

POM-method (Preventieve Ondersteuning Mantelzorgers) is a preventive method to support informal caregivers practically, systematically and methodologically. In the mental health sector prevention work is very important, not only for patients, but also for their informal caregivers. With every new intake of patients the informal caregiver is made a part of the care plan. House visits are carried out by trained social workers to provide information to the informal caregiver about the illness of the patient and the support services for informal caregivers. Mediant, the organisation for mental health care in the eastern part of the Netherlands, has received a prevention award for this method!

The main objectives are to prevent informal caregivers of older people with problematic behaviour from severe burden and low well being, by reinforcing personal resources, by improving knowledge, attitude and capacities of the caregivers; by strengthening social resources and reducing objective burden by facilitating respite care, day care, admissions, support from volunteers and by sharing care with other members from the social network.

As soon as a client is in contact with a health service for elder care, the informal caregiver is involved in the process of care. A private conversation with the informal caregiver is arranged by a trained POM-worker where problems and needs for support are discussed (for example with the EDIZ-scale, Pot et al., 1995). After this, information adjusted to the needs of this particular informal caregiver, is provided. A guide for informal caregivers is offered, and if necessary the POM-worker refers the informal caregiver to other specialists or arranges a second conversation. Two weeks after the last conversation the POM-worker calls the informal caregiver to ask about the informal caregiver's actions to arrange support. Three months later another call will be made. All this will be filed in a special informal caregiver record.

Support services for informal caregivers are divided into four categories:

Information, advice and emotional support	Support groups, courses for caregivers, information meetings, written information, telephone service for caregivers, digital information, counters with local governments, support centres for informal caregivers, care broker, take care of yourself-weekends (respite care)
Practical help	Meals and groceries services, handyman services, respite care services
Material support	Different arrangements for care aids, financial compensation and care leave
Representation of interests / interest groups	Patient and older people's organizations, interest group for informal caregivers (LOT)

Examples of services in these categories:

Information, social/emotional support, and advice

Support centres for caregivers (co-ordinated by Xzorg) are an important source for caregivers of information and advice about different aspects of caregiving (e.g. training in caregiving, information about financial aspects, care aids etc.), but also for social and emotional support (e.g. support groups).

Practical support

Various formal and voluntary organisations provide respite care either at the home of the care receiver (professional and/or voluntary respite care at home) or in health care institutions (e.g. day care facilities, care hotels (Zorghotels)) or in the community (e.g. Respite Pensions (Logeerhuizen), day care facilities in the community).

A number of organisations organise vacations for caregivers and the people they take care of. They go on holiday together and part of their care will be taken over from them by formal and/or voluntary caregivers. Costs are usually high (e.g. Nederlandse Rode Kruis, Zonnebloem, Nederlandse Hartstichting, Stichting Mens en Samenleving, Alzheimer Nederland).

The travel organisation Holiday & Care (Vakantie & Zorg) has selected different hotels in the Netherlands where the older person and the family carer can stay and receive the same type of care as they have at home.

Take care of yourselves-weekends (Zorg voor jezelf weekenden: LOT): weekend stay in hotels with other informal caregivers.

Norway – NO

Good practice

The Norwegian Health Association - For the Norwegian Health Association, a national voluntary organisation, dementia is one of its main issues. The aim is to work for the best life conditions possible for persons with dementia and their relatives. The organisation has established special "dementia contacts" in all of the 19 counties and 119 local associations for dementia caregivers throughout the country are registered (November 2003). Among other objectives, the organisation works to provide information about dementia and place caregivers' stress and need of support in public focus and start support groups. The organisation operates a special journal and a free telephone service for everyone needing advice or someone to talk to with respect to dementia. The "Dementia forum" offers information and opportunities to exchange experience on the Internet and by E-mail. The "Dementia Federation" within the organization co-ordinates both central and local work. This federation operates under a 10 point program of principles. Four of the points are especially concerned with the needs of family caregivers, e.g. for intervention and follow-up of the families of persons with dementia and to have available information and training for everyone. It is emphasised that the family caregivers' willingness to care does not free public authorities from their responsibilities to co-operate with and support the families. To attend to the real needs of each family the municipalities have to offer adequate and flexible services. The principles state that the families of persons with dementia should be given economic compensation so they are able to maintain their previous standard of living.
(http://www.nasjonalforeningen.no/)

"Schools for caregivers" have been established in Oslo and other places in Norway, operating in co-operation with the local organisations for caregivers of persons with dementia as well as with other organisations. They arrange courses for caregivers with lectures and group discussions on dementia, on the situation of the caregivers and on other relevant issues.

The Norwegian Centre for Dementia Research in Oslo/Sem was established in 1997 as a national "Centre of competence" for research and development projects to give better services to persons with dementia and their relatives. Its main tasks are to develop and give information on dementia, to offer counselling and consultation to the municipal and specialised health services and to develop new models of services and care for persons with dementia. The Norwegian Centre for Dementia Research organises courses all over the country and has widespread publication and information services. Projects include one on dementia in persons younger than 60 years of age. (http://www.nordemens.no/)

Other research centres also operate relevant projects for family caregivers e.g. NOVA – Norwegian Social Research, on dementia from a couple perspective (http://www.nova.no/).

An example at the local level is GERIA, a Resource Centre for Dementia and Psychiatric Care of the elderly, a service under the Department of Primary Health Care and Social Affairs, City of Oslo. Help to family caregivers is especially mentioned as an objective. A project on collaboration between staff and relatives of persons with dementia in institutions is in process.
(http://www.geria.no/)

In Oslo, "The Memory Clinic" at Ullevål University Hospital is a polyclinic for diagnosis of dementia and follow-up of both the persons with dementia and their close relatives. The Rosenborg centre (Oslo) is a unit for diagnostic considerations and treatment for persons with failing cognitive functions, with an emphasis on psychosocial aspects.

Gerontopsychiatric/psychological polyclinics and units for older people and their families are not fully developed in Norway. There are great variations in availability and the differentiation of the services offered varies between different parts of the country. Most "Family clinics" do not give special attention to the problems of elderly families. It is a national goal that everyone should be guaranteed the necessary health services regardless of age, ethnic or social background, or economic and geographical circumstances in "The plan for Stepping up of Mental Health services."

Terminal care - The "Fransiscus-help" (Fransiskushjelpen) located in Oslo, offers free service consultation on pain relief, care and nursing to terminal patients who want to spend their last days at home. Included in the service is consultation and support to family caregivers of the terminal patients as well as respite care. Caregivers with long lasting care tasks and persons in grief are other target groups for this well-regarded service.

Hospice Lovisenberg (Oslo) is an example of a unit for terminal care. It is based on the hospice ideology with holistic care both for patients and families. The unit accepts patients from the eastern part of Norway for day or day and night care.

The Norwegian Association of Palliative Care has been active in pointing to the needs of palliative care for elderly and their families.

Innovative practice

New technology – E*NABLE,* with partners from England, Ireland, Finland, and Lithuania, the Norwegian Centre for Dementia Research participates in this EC funded Programme "Quality of Life and Living Resources”. The project aims at facilitating independent living for people with early dementia and to promote their wellbeing through access to enabling systems and products. In Norway, 25 persons with dementia and 25 family carers are involved in the ENABLE trial assessment. Products tested are: night and day calendars, picture telephones, locators (of lost objects), and medicine reminders (programmed with an automatic sound). Most respondents are satisfied with the products, they find them useful and they use them. The products that are most popular in Norway are the night and day calendar and the medicine reminder (www.enableproject.org).

Action. 'Action' stands for: Assisting Carers using Telematic Interventions to meet Older Persons' Needs. The 'Action project' in Nøtterøy, Vestfold County is organised in co-operation with the College of Borås, Sweden, based on an EU-project. The main aim is to support frail older people and their families to maintain or enhance their quality of life via the use of user-friendly information and communication technology in their own homes www.action.hb.se/.

"Project on Caregivers" (GERIA) focuses on the relationship between staff and family caregivers, after the person with dementia receives formal care from institutions or day centres. The project includes staff and family carers in four institutions and uses a variety of methods: questionnaires, lectures, group discussions and one-to-one-collaboration between staff and family carers. An

earlier project from GERIA focused on collaboration contracts between staff and family carers. (http://www.geria.no/)

"Visiting service" to persons with dementia The Norwegian Red Cross (www.redcross.no) has an organised service of visits to older people in need of social contact. In collaboration with GERIA, the organisation of caregivers and the "Fransiscus help", the "Red Cross Visiting Services in Oslo" offer special courses for volunteers who want to be visitors of persons with dementia.

The **National Council for Citizens** is an advisory board for public authorities and national institutions. The council focuses on issues concerning living conditions of senior citizens, and their opportunities to take part in working life and society at large. In particular, the council has its attention on politics concerning senior citizens with special needs for nursing and care. The council has existed since 1970 and functions as a useful channel of influence directly to Government organs for family caregivers as well as other interest groups.

On a local level the "Councils for Senior Citizens" in the municipalities have a similar function.

Norwegian senior centres and volunteer centres - Senior centres have a history of more than 50 years in Norway, with ca. 330 centres and 130 000 elderly users. In addition Norwegian volunteer centres have been established since 1991. In 2001 more than 200 volunteer centres were registered. Voluntary initiatives on health and social affairs have been, and still are, central to the work of these centres. Older people (60+) are the largest group of both users and volunteers. Examples of help include: bringing meals, transport and accompany services, visits, gardening, etc. This is useful both to the person in need of help and as an assistance to the formal service system and to family caregivers. A recent report emphasises a shift in the profiles of the volunteer centres over the years, where the care-perspective has become somewhat downplayed. Three activity profiles are mentioned: the "care centres" with a relatively narrow orientation towards social and practical tasks; "Community centres" sees the centres as a driving force in building social neighbourhoods in the community as a whole. The most common activity profile is the "meeting-place centre" which has a broad repertory of social care activities as well as recreational and community activities. Self-help groups and groups for caregivers are often organised in connection to or in collaboration with voluntary centres.

Poland – PL

Good practice

Article 18 of the act on social care states that local authorities decide on the range and place of providing care services. This creates the possibility for both the creation of small family care homes and large care service centres. Their functioning however is dependent on the possibilities of providing transport for people using the care services. The same regulations create the basis for periodical use of help from the community nurse by older people when their family carers are away. Another way of substituting family carers is to use the help of voluntary workers and local institutions which offer short term use of their services.

Innovative practice

One of the aspects of the use of this regulation is the initiative of creating Centres for Social Services (CSS) on a local level. Such centres are supposed to combine social and medical functions for economically impaired social groups. As a sort of return to the idea of integrated socio-medical care they are supposed to stress the role of the family and informal groups in providing for the needs of and caring for older people. Self-help groups and non-governmental organizations which are partners in providing care would also find support in CSS. Health care activities would concentrate on rehabilitation and nursing for people chosen by the family physician and community nurse. Social functions go further than just providing necessary financial support and aim at creating conditions under which older people can take part in the life of the local community. Rehabilitation equipment would be available in the centre as well as services connected with repairing it. The above possibilities are still a matter of study projects but have no base in any act of law.

In regions which now use or used to use financial help and counselling from West European non-profit organizations, a practice has developed of creating non-governmental organizations working by the rules of Maltese help, that is substituting or supplementing family members in their care functions. Such organizations can provide transport for disabled elderly and supply basic goods and services as well as instruct family carers.

Portugal – PT

Good practice

The *Program of Integrated Support for the Elderly* aims to ensure the provision of care of an urgent or permanent nature in order to maintain the autonomy of the older person in his/her own home and in his/her family environment; to establish the means to ensure the mobility of the older person and access to benefits and services; to implement support for families who provide care and support to dependent family members, namely older people; to promote and support initiatives for the initial and in-service training of professionals, volunteers, family members and other people in the community; to promote attitudes and measures to prevent isolation, exclusion and dependency and to contribute to intergenerational solidarity as well as creating jobs. Within the scope of this program the following initiatives were carried out:

Home Support Service (SAD): aims to keep elderly and dependent persons in their normal living environment, close to their family, neighbours and friends. In this initiative, projects are developed which take into account the breadth of existing coverage, the extension of 24-hour support, the improvement of the quality of the services provided and the adequacy of the home environment to the needs of the elderly persons.

Support Centre for the Dependent / Multidisciplinary Resource Centre (CAD): These resource centres for temporary support are open to the community and focus on prevention and the rehabilitation of dependent persons. They are developed on the basis of already existing structures, providing a range of support and care with a view to promoting as much autonomy as possible and the continuation of an active life project. The institutionalization component, which this response may encompass, is developed in small units of a family and humane nature, with

strong links to the home support service, creating conditions for the participation of the family and a return to the habitual living environment as rapidly as possible.

Human Resource Training Centre (FORHUM): designed for family members, neighbours, volunteers as well as for health and social service professionals and other members of the community, enabling them to provide formal and informal care.

Grandparent Plan: This plan was conceived to develop a process of revision of the legislation on residential care for elderly people, renovations or replacement of elderly people's facilities, repairs to their homes and the widening of the home support services. Additionally, it aims to improve the training of staff involved. As a main goal, this plan aims to define the process of certifying institutional quality.

National Action Plan for Inclusion (PNAI): defines as priorities the improvement of support for dependent persons and the development of actions centered on preserving family solidarity. It relies on the information society and the knowledge economy to overcome backwardness. Special attention is given to the disabled. One of the objectives of PNAI is to develop initiatives designed to preserve family solidarity in all its forms.

Integrated Response – social action and health (Dispatch Collection nº 407/98,15th May). The target group is people who are physically, mentally or socially dependent, temporarily or permanently. The objectives are the promotion of autonomy and reinforcement of the capacities and skills of families in relation to the treatment and accompaniment of these situations.

Switzerland – CH

Good practice

Family carer work for an elderly relative is not well recognized and is underestimated in Switzerland except in some regions such as the canton of Fribourg, a pioneer in supporting family care, which in 1993 adopted legislation where the commune allocates 25 Swiss Francs per day, equivalent to 750 Swiss francs per month to the 'natural caregiver' providing home care to an elderly member of their family. Many discussions took place concerning the criteria and definition of the 'natural link' with the elderly person. In order to get financial support from the municipality, care needs must be substantial and daily for at least 60 days. A daily allowance is given after the assessment of a home nurse through a grid assessment. In 2001, in the Southern part of the canton, in Gruyère, 137 women and 37 men received this allowance (15 husbands, 43 spouses, 43 daughter in law and 10 nieces)

Family care should not be disadvantaged in favour of institutional care nor give an incentive to local authorities not to develop professional help care and relief systems.

Innovative practice

Technology allows the disabled person to increase his/her autonomy and safety (e.g. alerting relatives), and accommodate the needs of today's older people, for whom autonomy and safety represent the highest values.[7]

The Swiss programme on Ageing supported a large research on innovative technology and home care of the elderly. This showed that daily life and activities (such as telephoning, keeping house etc.) was facilitated by electronic aid without the need to re-organize daily living or introduce new activities. It was also found that the use of electronic aids neither promotes the isolation of older people (less contact, as more independent) nor increases social contact. Social consequences occurred insofar as the relatives and carers of the older people felt more secure (above all if a telephone alarm had been installed, but also if telephoning had been made easier). The older people themselves also felt safer, e.g. being able to call for help in an emergency and this feeling of security relieved the burden on social relationships, especially on all the relatives who could not look in daily or lived further away. The feeling of greater security meant moreover, that the autonomy of the older people also increased as they themselves could decide when they needed help. Today, more and more age-friendly technological devices exist and are being developed in Switzerland to ensure a longer stay at home and facilitate the efficiency of home care and security (e.g. tele-alarm systems, video camera, phones with big digits, etc.).

Quo Vadis, a passive electronic device for mentally dependent older persons, was experimentally used in a diverse type of homes for the very dependant or demented older people as a way of relieving health care professionals from the continuous surveillance of the older person, through a system of monitoring and alarm cells placed in different areas of the building. While allowing a certain degree of free mobility to the patient, at each of those points, the position of the patient is known, especially if the institutional border is transgressed. This passive electronic aid proved particularly valuable for non-specialized old people's homes as they make it possible to admit a mixture of patients. Thanks to suitable aids, both the private sphere of residents can be better safeguarded (for example, against unauthorized entry) and the safety of confused people better guaranteed. Fewer conflicts occur and the burden on staff (unnecessary checks, anxiety) is reduced, which also benefits the older residents. On the basis of the pilot study and experience gained, the electronic security system for residential and nursing homes of the Neuchâtel 'Fondation Suisse pour les Téléthèses' has been further developed and marketed under the brand name of 'Quo Vadis'.

This device is promising as it could well be adapted and applied in the future for home care.

It should be mentioned that the Internet is being increasingly used by active senior citizens, and corresponding courses find a large response. Since May 1998 there has been a special **senior citizens web**, which is supported by EURAG, the Pro Senectute and Migros (http://www.seniorweb.ch). In this context, e-health and e-care is rapidly developing for all age

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[7] The possibilities and advantages of electronic aids for elderly people are introduced and illustrated by a special NRP32 video film: A. Jolliet (1997) Vieillir heureux chez soi. Techniques and domestic aids in the service of elderly people, Geneva: Univideo Genève (German version: Glückliches Altern zu Hause, Italian version: Invecchiare felici in casa propria) (video duration 26 minutes). Information under: http//www.unige.ch/univideo

groups and setting a new health behaviour pattern that might well become a substantive part of future family home care management.

Slovenia – SI

Good practice

Valuable help to families with older people is offered by associations and other non-governmental organizations. Associations are usually linked with the central European association for self-support in its field, they publish informative papers for their member and the wider public, organise training, vacations and other events. The non-governmental sector still provides most help to family carers of older people. But these associations are frequently local, so that their help is not available at the national level. Family carers living in the capital have the most favourable conditions with an association that employs 9 people and has 591 members, a lot of them volunteers.

The Slovenian Hospice Association has been active since 1995. Activities are carried out through regional boards at the national and local level. Their purpose is to help close relatives and health care personnel in work with the dying, to do away with taboos about dying and help the grieving. In 2002, the Association worked with 150 dying patients and 302 close relatives of cared-for patients. 77 volunteers helped families through 1529 voluntary hours. The average care period was 49.5 days. In 89 cases relatives of dying patients were provided with individual consultations and a lot of distressed people asked for advice and support. In line with the philosophy of the hospice, relatives are visited for at least 13 months after the patient's death. In 2002 the Association thus worked with 128 relatives. Some relatives were treated individually; others joined support groups for the grieving. The Association allocates 49% of its funds to this project.

Grief support - The target group are the grieving who have lost a close person. Work with the grieving is performed on a voluntary basis, except in the capital. In 2002, 347 individual consultations throughout Slovenia were given, a lot of them also at the Association's office (228) for 109 people. They also offer 5-hour educational workshops, entitled "When a person is left alone". These are intended to all people who cannot participate in a support group for the grieving for various reasons. There were 7 workshops in different places throughout Slovenia. Support groups for the grieving meet on a weekly basis. In Ljubljana, one group was formed for adults who have lost a parent (9 members). Besides the above mentioned activities, there is also a relatives' club, operating as a monthly social gathering for an average of 3 hours. These meetings are held in Ljubljana, Maribor and Celje. The Association allocates 15% of its funds to this project. The Association also plans to open a hospice house within the City Municipality of Ljubljana offering five apartments for dying patients, a day-care centre for dying patients and a consultation centre for health and social workers. The high costs mean this project is not yet realised.

"Forget-me-not", the Alzheimer's Disease and Related Disorders Association of Slovenia helps patients, close relatives, expert associates and non-expert carers in overcoming problems arising from dementia and other mental disturbances of old age. It was founded in 1997 in Ljubljana in cooperation with the Psychiatric Hospital Ljubljana. The Association also provides education, informa-

tion and advice to family members and informal carers. This association has a special programme *Forget me not*, which is intended for close relatives of demented patients still living in their home environment. Meetings are weekly and are held over nine consecutive weeks at the premises of the Psychiatric Hospital Ljubljana. Each meeting lasts for 90 minutes. The educational part is followed by a discussion intended to solve problems. It also offers relatives a consultation phone line and self-support groups for relatives of demented patients, who wish to share experience on the disease of their closest relatives.

Innovative practice

Training of families for better communication with older family members – the Anton Trstenjak Institute - Within the network of intergenerational programmes for quality of life in old age, the Institute implements a 10-hour course to train families for better communication with older family members. The course offers participating family members the chance of gaining knowledge and techniques concerning essential changes in the family in the transition from a traditional to post-modern setting, the basic rules for successful family communications, the characteristics of ageing and old age necessary to understand older people, how to solve concrete problems and specific tasks to improve relations between the family and its older members. Most violence against older people is committed by the closest relatives, who are not aware that their words, silence and behaviour are violent towards aged parents. The course shows how better communication with older people provides younger generations with several benefits at the same time: the quality of life of older family members is increased, everybody is happier due to improved family relationships and younger generations become familiar with old age. The course is carried out in line with the social group learning method.

One of the results of this programme is also the "Club of relatives". During the training process, relatives of people living in old people's home expressed the wish to have meetings also after the end of training, so they formed a club within the old people's home. Their monthly meetings are supervised by a social worker from the old people's home. They discuss different topics that concern them and their older relatives.

Spain – ES

Good practice

Good practices are scarce bearing in mind the general scarcity of social services, although they are increasing.

In the autonomous community of the Canary Islands, within its government "Programme of attention for the Elderly in Primary Attention", a programme has been established of support to carers which offering training activities to 100 % of carers and promotes plans of community support (self-help groups, associations).

Innovative practice

Guipúzcoa county hall (autonomous community of the Basque Country) offers the Sendian programme for the support of carers, which comprises different resources: family training, psychological support, self-help groups, weekend breaks, long term breaks, technical help, volunteer programs, economic aid and tax exemptions. The programme is structured in a co-operative agreement between San Sebastian city hall and the provincial council, and is offered to all families providing care.

Galicia is the only autonomous community where the "Assistential Cheque" has been used (Galicia Government, 2001). It intends to help dependent older people to meet the cost of being cared for. The programme focuses on those who are very dependent in their activities of daily life, and have scarce economic resources. It takes various forms: residence cheque, day attention cheque (day centres), cheque for attention in the home, cheque for temporary stay and programmes of family rest.

Madrid also runs a Carer Subsidy.

The Vida als Anys programme in Catalonia, is an example of management of assisting services and good co-ordination between health and social services;

Sweden – SE

Good practice

In the table below, the coverage of different types of support programs for carers is presented.

Table 1: Availability of support programs for carers (% of municipalities providing)

Type of programme	Available in 1999	Available in 2002
Economic support	66	63
In-Home respite care	69	87
Institutional respite	99	97
Day care	80	92
Carers support group	28	83
Carers resource centres	7	56
Carers consultant	5	68
Counselling	47	77

Innovative practice

Innovative respite programs

Respite services are now available in virtually all of Sweden's 290 municipalities. Especially *in-home respite* care has become a very popular support program with an increasing number of municipalities offering in-home respite, free of charge. There are also interesting trends towards more innovative types of respite services. This involves greater variation and scope of different types of relief services. Here the ultimate goal is to be able to offer carers "24-hours instant relief" or drop-in services. Some municipalities also offer this service without (or with minimal) bu-

reaucracy, in order to maximize access to relief for the carers. Respite could be combined with "weekend-breaks", when carers are offered stays at spa-hotels, in order to stress-down, take time out, and care for themselves.

Counselling programs

Interestingly, there has been a substantial growth in counselling and personal support services provided in the municipalities. This has become a vital part of the core package offered to carers. This is at the same time a good example of collaboration between formal services and the voluntary organisations, as e.g. support groups are often run by voluntary organisations, as well as befriending and sitting services and help-line services, all over the country.

Information and training programs

Another trend is to develop richer opportunities for information using modern IT-technology, educational and personal counselling services. Training programs, seminars and conferences, addressing both politicians, care personnel, carers and their organisations have been carried out all over the country in recent years. Many local authorities have also developed different types of out-reach strategies. Finally, another popular idea is to appoint a "Carers Consultant", at "Carers Centres", who functions as a two-way co-ordinator of contacts between the formal services and the carers.

United Kingdom – UK

Good practice

Good practice for carer assessments and support is provided in the guidance that accompanied the Carers and Disabled Children Act 2000.

Quality standards for carer services were defined following the Carers National Strategy as follows (the following is a verbatim account of the Executive Summary, obtained from www.carers.gov.uk/qualitystan.htm):

- The following standards are based on carers' views of service quality and are broadly supported by carers and managers and practitioners from voluntary, health and local authority services who took part in a wide consultation process.
- Many respondents stressed that above all else action is needed by mainstream health, community and social services to deliver good quality support to disabled, ill and frail people. These services also need to better recognise and respond to carers and ensure carers can get help and substitute care in an emergency, a break from caring and night cover.
- The standards are primarily designed for services exclusively aimed at supporting carers, for example: carer centres, carer support projects, carer groups and services designed to offer carers a break, special help or advice.
- However, these standards are equally relevant to mainstream health, housing, education, community and social services who will need to address these carer quality standards as well as other quality standards related to the modernisation of health and social services and local government.
- It is recommended that as a pre-requisite for providing a quality service, **all** carer support services should demonstrate they meet four essential requirements:

  - carers from all local communities are effectively involved in the organisation;
  - the service works in partnership with all local agencies;
  - the service is clear about its principles, aims and how these will be delivered and monitored;
  - all staff, including volunteers and trustees, are appropriately trained and supported.
- It is proposed that any service aiming to provide carers with information, a break, emotional support, support to care and maintain carer's own health or support to have a voice will need to meet the relevant standard and accompanying list of conditions.
- The five key standards are:
  - *Information:* Any service providing information to carers, provides information which is comprehensive, accurate and appropriate, accessible and responsive to individual needs.
  - *Providing a break:* Any service offering a break to carers, works in partnership with the carer and person being supported, is flexible and gives confidence and can be trusted.
  - *Emotional support:* Any service offering emotional support to carers, either on a one-to-one basis or in a group, is sensitive to individual needs, confidential, offers continuity and is accessible to all carers.
  - *Support to care and maintain carer's own health:* Any service which supports carers to care and to maintain their own health and well-being by offering training, health promotion and personal development opportunities is responsive to individual needs.
  - *Having a voice:* Any service which supports carers to have a voice as an individual and / or collectively is accessible to all carers and is able to act in an independent way.
- It is proposed these standards for services directed exclusively at carers are monitored through contracting processes. Contracts between the funding organisation and the carer support service should include these standards and evidence for meeting each condition obtained systematically as part of the agreement.
- Organisations providing local carer support services should be encouraged to carry out self-audits and continue to develop their own quality assurance schemes in order to deliver these standards.
- Recommendations from the consultation for action centrally and locally to put these standards into practice include:
  - Support local partnerships between carers, statutory and voluntary organisations to address these standards constructively, ensuring no small voluntary or community organisation are disadvantaged.
  - Ensure mainstream services meet these quality standards as well as standards for services to the person being supported.
  - Support carers to have a key role in monitoring the quality of services.
  - Give priority to ensuring carers from all communities are included.

Innovative practice

There are now several innovative schemes for carer support. The previously cited Audit Commission report on services for carers (Audit Commission 2004e) provides details of a number, including:

- A primary care booklet to identify carers.
- A recognition and discount scheme to aid in the identification of carers.
- An Internet site for carers (www.carersnet.org.uk) linked to Carers UK national website (www.carersonline.org.uk):
- GP attached carer support worker service.
- Voluntary organisation carer database, information and support centres.
- Initiatives to encourage carers to take up services / benefits.
- Intensive carer support schemes.

More detailed descriptions of these and other schemes can be found in the report.

The **Audit Commission (2002, 2004a, b, c)** provides numerous case examples of innovative practice in their series of reports that map a vision for integrated services for older people and further develop that vision with respect to the promotion of their independence and well-being. These include, for example, initiatives aimed at:

- Identifying vulnerable older people / screening and case finding
- Mapping and redesigning service provision
- Neighbourhood community care schemes
- Keep well at home / active ageing / health mentor schemes
- Joint case management arrangements / case management models
- Services to promote intermediate care, hospital discharge and rehabilitation
- Better assessment practice
- Housing strategies for older people
- Care direct (telephone advice) schemes
- Senior surfer projects
- The role of champions in sustaining political support
- Involving older people
- Medicines management

Fuller accounts of these schemes can be obtained from the above reports available on the Audit Commission Web-site (www.audit-commission.gov.uk).