Dementia in my family

Taking an intergenerational approach to dementia

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ILC

Alliance for Health & the Future

Alzheimer Europe

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Foreword

There are currently 5.5 million people with dementia in Europe. There are more new cases of dementia per year than of stroke, diabetes or breast cancer. With the ageing of the population and no cure in the foreseeable future for dementia, these numbers are bound to increase in years to come.

Despite its high prevalence, awareness of dementia is low. Fear of what it entails is widespread. The terms ‘dementia’ or ‘Alzheimer’s disease’ conjure up images of frailty, dependence and loss of dignity that none of us wishes to face. Nobody wants dementia to be ‘their problem’. Nobody wishes to entertain the possibility that they, their loved ones, or their neighbours, might get dementia. None of us is prepared for the toll it may take on our family or community if it affects someone close to us. Moreover, our public services are poorly prepared in terms of home care services, residential and respite care spaces, staff training and support services to care for those affected and their families.

We can no longer afford to be in denial. Dementia is too prevalent and its toll on our society is too great for it to be the sole concern of those affected by it: **it should be a concern for all of society and for all generations.**

If all generations can understand dementia better, then fear of the condition may be dissipated and, with that, denial and stigma may be lessened. More families will recognise symptoms earlier and seek appropriate treatment that may delay progression of the disease. And more communities will succeed in obtaining the resources and funds they need to ensure that the quality of life of individuals affected by dementia and their families is protected throughout the course of illness.

The purpose of this report is to help promote an *intergenerational approach to dementia*. The report begins by highlighting key facts about dementia. It then describes the role that the family plays as well as the impact of dementia on the entire family. We then move on to looking at successful initiatives across Europe in which different generations work together to lessen the burden of dementia in their communities. Finally, we propose ways in which we may support all generations as they cope with dementia within their families.

The report is based on a workshop held in June 2006 at the European Social Services conference in Vienna. Workshop presenters were Barbara Pointon, carer; Noreen Siba, International Longevity Centre-UK and Alliance for Health and the Future; and Jean Georges, Alzheimer-Europe. All conference presentations and background papers are available on the conference website (www.socialeurope.com). The workshop and this report were made possible due to an unrestricted educational grant by Pfizer.

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Dementia in our society

Prevalence

Dementia affects 2% of 65-69 year olds but some 22% of 85-89 year olds (EuroDem 2004). With the ageing of the population, the number of people with cognitive impairment is expected to rise by over 60% over the next 30 years. Dementia can also affect younger people; however, its prevalence is lower.

What is dementia?

Dementia is not a single condition. It is an umbrella term which encompasses several forms of cognitive decline, of which Alzheimer's disease is the most common [1]. A simple and practical definition of dementia is: 'the loss of intellectual functions of sufficient severity to interfere with a person's daily functioning (Alzheimer's Association, www.alzgmc.org/about_alz).

The symptoms of Alzheimer's disease usually involve a slow and gradual deterioration of a person's ability to function in daily life. Brain damage caused by the disease progressively affects mental functioning (memory, attention, concentration, language, thinking, etc) and this in turn can have repercussions on behaviour (Alzheimer's Association, www.alzgmc.org/about_alz).

Alzheimer's disease usually progresses through three stages: mild, moderate and severe. The average duration of the period from diagnosis of Alzheimer's disease until death is about 5 years – however this may vary significantly from one person to another, and symptoms may increase rapidly over the course of many years. **The course of illness thus varies significantly from one person to another, as does the need for care and family support.**

The cost of dementia

The emotional, clinical and economic toll of dementia is considerable. Care for dementia presents a huge cost for our health and social care systems, particularly residential care. In the UK alone, the cost of dementia is thought to be £17 billion per year (Alzheimer Society, 2007). A further UK study estimated that the costs of long-term care for people with cognitive impairment would need to double from 1998 to 2031 to meet demand (Comas-Herrera *et al,* 2003).

Many of the costs of dementia, however, are hidden. Lost productivity of those affected and the people who care for them, the financial and emotional costs to families and the cost of informal care are rarely included in estimates. If they are, the methods for quantifying them vary significantly between studies – and so do the estimates themselves (McDaid 2001).

The social costs of Alzheimer's disease – namely those borne by families – are often underestimated. As a result, **estimates of the cost of dementia often do not tell the whole story of the heavy burden of dementia on our societies.**

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[1] For simplicity's sake, the term 'Alzheimer's disease' will be used throughout this report instead of dementia. This reflects the fact that most of the literature is on Alzheimer's disease.

Caring for Alzheimer's disease

Treatment options remain scarce for Alzheimer's disease. The cholinesterase inhibitor drugs have been shown to improve the affected person's quality of life, reduce the impact of symptoms and sometimes delay the progression of the disease. Other forms of help, such as cognitive therapy, counselling, psycho-social stimulation, day care and support groups can also play a critical role in improving quality of life throughout the course of illness and in some cases have been shown to bring significant improvements in the symptoms of dementia. Yet, although the benefits of these treatments may be clear to families, they have not always been taken seriously by professionals or regulatory authorities. As a result, availability of treatment options and access to these treatments have been limited in many countries.

Even if services are available, they are rarely fully funded by the state. Care for dementia spans health and social care, and is provided by the public, voluntary and private sectors. Services are subject to bureaucratic barriers due to separate funding streams and lack of coordination. Efforts at integrating care are slowly helping to eliminate these barriers, but success is very incremental.

For much of dementia care, individuals still need to pay for services out-of-pocket.

The role of informal care

Because of limited treatment options and the chronic nature of Alzheimer's disease, the bulk of care often rests on the shoulders of family members or informal carers. Families may eventually resort to placing a relative into a care home, usually either at a point of crisis or at the more advanced stages of the disease.

An American study estimated that, on average, informal carers provide 13 hours of care per week for someone who has mild dementia, but this number **rises to 46 hours per week** for someone with severe dementia (Langga et al, 2001). It is the *combination* of cognitive impairment and physical limitations that is particularly demanding and potentially devastating for the family to deal with.

'Partners and relatives have to cope with the emotional toll of seeing a loved one's cognitive abilities decline, as well as the challenging behavioural aspects of dementia, including aggression, wandering and insomnia. All these symptoms can contribute to the mounting loss of activities of daily living (ADL) abilities, and it is the combination of cognitive impairment with ADL disabilities that creates particular challenges for carers.' (Poole T, 2006).

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Alzheimer's disease in our families: the impact

When Alzheimer's disease strikes, family dynamics are irreversibly altered. All family members are likely to be deeply affected. Each member may go through successive feelings: denial, anger, frustration, despair, anxiety, sadness, before managing to come to some sorts of terms with this devastating condition. They may withdraw into themselves and feel embarrassed or ashamed of the condition, and aware of social stigma and the negative attitudes of others. Often several of these feelings are experienced at the same time. However, family members do not have the luxury of taking care of themselves when faced with the immediate needs of a loved one affected by dementia.

The effect on family members: the partner or spouse

Depending on the family configuration, it is most often the partner or spouse who is the main carer for the person affected by Alzheimer's disease. It is almost impossible to imagine the emotional impact of seeing the person with whom one has shared a lifetime undergo the dramatic changes brought on by dementia. It is not only the feeling of gradually losing touch with one's partner; sometimes the changes of dementia can make it feel that you are living with a stranger. But despite all this, the vast majority of partners of people with dementia value the continuity of their relationship and choose to continue to care as long as they are able.

> *"What has all this done to me? My hobbies and social life have shrunk – I used to conduct choirs and orchestras, was involved in politics, directed plays and musicals, enjoyed entertaining. Now even my garden is sadly neglected. All activities outside the house have to be planned for and cover arranged. The huge loss of spontaneity and freedom to be able to do what I want at any time – such as pop out for an hour to see a friend – is hard for anyone not in this situation to comprehend. The stress has started to undermine my health. I'm on duty or on call 142 hours a week."* – Barbara, carer

The financial impact of Alzheimer's disease on families can also be devastating. Most carers at some stage have to stop working and rely on pensions and state benefits. More often than not, the partner will also have to give up his or her job, let alone leisure time or a social life. Much of the care needed for dementia is in the domain of social care, which may be means-tested. Families thus often bear huge financial costs to ensure that their loved ones receive appropriate care.

Siblings and friends

Siblings or friends who do not live day-to-day with the person affected by Alzheimer's disease may find the sudden changes in behaviour and cognition difficult to deal with. **They may feel at a loss and not know how to engage with the person affected by Alzheimer's disease, particularly as verbal communication can become difficult.** They may be tempted to withdraw from their relative or shorten their visits, thereby increasing the isolation of the person with dementia, or even leading to neglect.

Here, guidance from the main carer and from support staff may help the person learn to rely on touch, non-verbal communication and to find ways to connect with the person affected by Alzheimer's disease.

The children

Because Alzheimer's disease most often occurs later in life, the children of those affected tend to be grown up when their parent is first diagnosed. Yet regardless of one's age, dealing with the fact that one's parent may no longer be able to play the role of providing guidance and advice may be very difficult to accept. It is difficult for a middle-aged adult to change into being the carer of the person who once cared for them. Seeing a parent behaving erratically, perhaps even aggressively, may be both emotionally distressing and frightening. The children of individuals affected by dementia need to be supported with the appropriate information, advice and guidance to help them adapt their relationships with their parent.

> *The children "have gone through the stages of being embarrassed, then accepting and now helping to care for him. It comes as a surprise to find yourself a volunteer in the silent army of carers – something you had never expected or planned, and certainly never received any training for."* – Carer

The grandchildren

Children tend to ask awkward questions outright – *Why can't grandpa talk? What is wrong with grandma's brain? Why can't she eat on her own?* Children will be affected by the disruption of their parents' lives, and they may become involved in practical caring tasks for their older relative. As a result, their social lives and education may suffer, whilst at the same time they, like their older relatives, have to cope with the distress caused by the illness.

Although one may wish to protect children, in many ways it is best to answer their questions simply and clearly. Children's books which treat the subject openly and sensitively can be very helpful (Alzheimer Europe).

One carer explained to her grandchildren that their grandpa's brain was like a computer and that the computer no longer worked. This type of 'normalising' cognitive decline may help children of all ages adapt their relationship with their grandparent or older relative as they need to.

Young children can benefit greatly from seeing illness as a part of life, not something shut away and to be feared. This education must start in schools – about health, illness and death. It must be extended to older children as well.

Can young people be willing carers?

Research has found that children are willing to provide care for older relatives affected by dementia. Stressful circumstances may originate, however, when a child or teenager is over-challenged by factors such as sole responsibility for a person with dementia, wandering symptoms or aggressive behaviour (Phillipp-Metzen, Heike Elizabeth, 2006). Children and young people are therefore best placed to engage with people with dementia as part of an existing and managed framework of care (ibid).

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An intergenerational approach to dementia

As has been demonstrated above, the family is the cornerstone for care and support when a family member is affected by dementia. Society has an important responsibility to create a positive environment which supports families affected by dementia. This has to start with creating greater awareness and empathy **across all generations** for dementia and what it entails.

How can this happen? We feel an **intergenerational approach** to dementia should occur at three levels:

- Families caring for a relative with dementia at home are offered the services and guidance they need to help *all family members and friends* cope and adapt.
- *Care homes* and other services which cater for people with dementia provide a welcome environment for all family members.
- *At a societal level,* targeted initiatives take place to help foster exchange between people affected by dementia and the younger generations.

We have identified eight avenues that may help achieve an intergenerational approach to dementia. These are listed in the box below and then described in further detail in the following section. When possible, we also present examples of successful initiatives from across Europe[2].

An intergenerational approach to dementia: what can be done?

i. Raise awareness of dementia across all generations
ii. Encourage early diagnosis and treatment of dementia
iii. Improve clinical and social care training on dementia
iv. Provide flexible services for families caring for relatives at home
v. Provide respite care for families caring for relatives at home
vi. Provide a welcome environment in care homes and in the community for all family members [there's really two here – dementia friendly services for people with dementia and carers, and dementia friendly communities – shops, police, churches, etc.
vii. Involve younger people in delivering services to people with dementia in nursing homes
viii. Foster innovative partnerships in the community to bring people with dementia in contact with younger people

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[2] Case studies were obtained through a literature search, selected interviews and a written questionnaire that was sent to all Alzheimer-Europe member organisations. In the survey, we asked respondents to identify specific initiatives aimed at encouraging different generations to work together with people with dementia. We are very grateful to the respondents as well as the individuals who provided further information by email or telephone. They are listed in **Appendix 1.**

i. Raising awareness across all generations

One of the biggest hurdles facing dementia is the low awareness and understanding of the condition across society. A better awareness of what Alzheimer's disease involves will help each of us to recognise Alzheimer's disease if it occurs within our families, and may help reduce some of the fear and stigma faced by those affected by the disease.

The Alzheimer associations and other advocacy groups for dementia play a vital role in providing critical information about the condition and its impact on those affected. However, we cannot leave this role to these groups alone. The government, the media, health and social care professionals all have a role to play in increasing general public awareness about the prevalence and impact of dementia on our society.

All of us need to shift personal beliefs and images of Alzheimer's disease, as well as address the 'double negative label' of being old and having Alzheimer's disease (Sartorius, 2003; Iliffe, 2005). We all must work together to **humanise and destigmatise the face of dementia at a societal level and in our local communities.**

Education about dementia can begin in the classroom. Guidance for parents and teachers to help children and young people deal with serious illness as an integral part of life should play a significant role in shifting the attitudes of the next generation.

Many of the Alzheimer's associations have created excellent reference materials, leaflets and resources to teach children and young people about dementia. A list of some of these materials is available in **Appendix 1.**

The Relatives' Club in Slovenia
Reducing the isolation of relatives

The Anton Trstenjak Institute launched a course to train families to communicate better with older relatives. One of the outcomes of the programme was the creation of a 'Relatives' Club'. Relatives of people living in an old people's home expressed the wish to continue their meetings after training finished, so they formed their own club within the old people's home. Their monthly meetings are supervised by a social worker. They discuss different topics that concern them and their older relatives.

Danish Students participate in a seminar on dementia

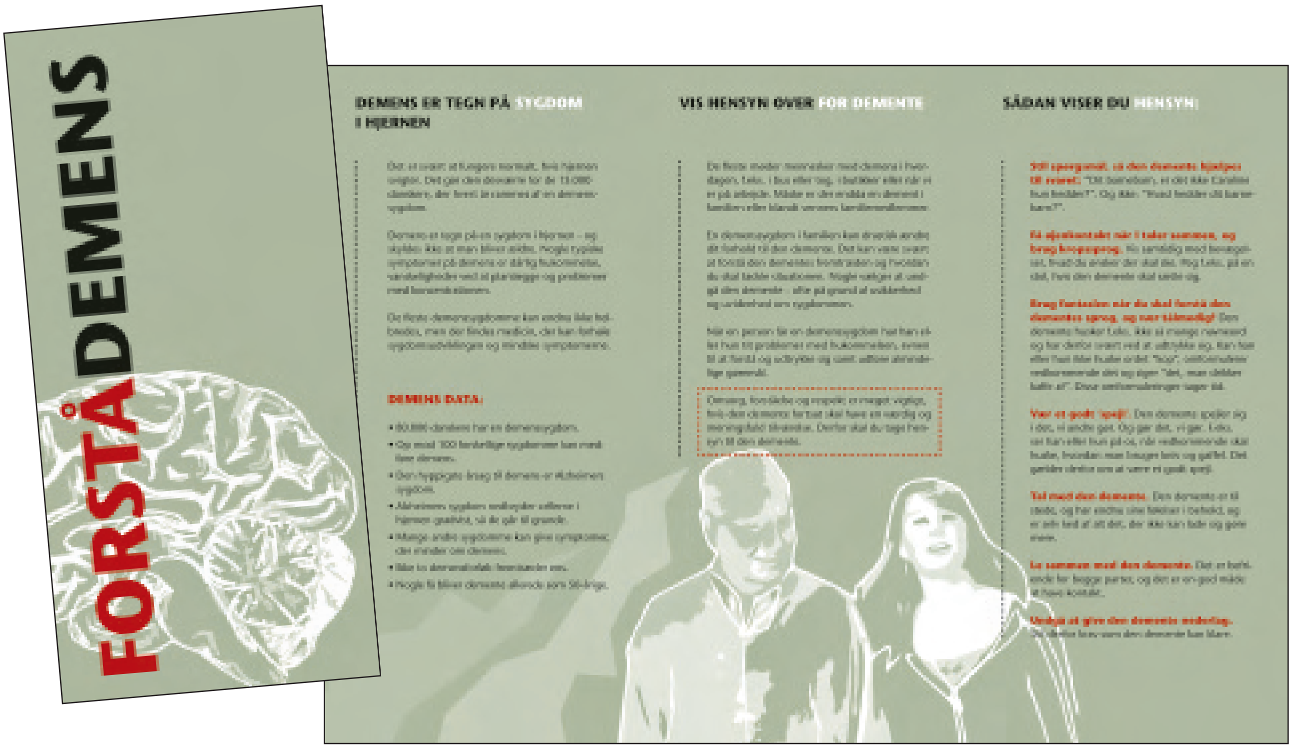
Educating secondary school students on dementia – Copenhagen

Copenhagen University Hospital and the Danish Alzheimer's Association in Frederiksborg carried out a joint project to educate secondary students on dementia. Two schools participated with approximately 130 students taking part in a two-hour lecture on the functioning of the brain and how it is affected by dementia related illnesses.

Although some of the students were related to people with dementia, they had little knowledge of the disease and how care was provided, other than what they had seen for themselves or been told by their peers.

The organisers felt it has been important to engage the students. Where possible, they made reference to the experiences of other people of similar age who were involved in dementia care. As a result of the lesson, 22 students signed up to act as volunteers distributing information in the community.

To find out more please contact **www.alzheimer.dk**
or project organiser **ane.eckermann@rh.hosp.dk**



FORSTÅ DEMENS

DEMENS ER TEGN PÅ SYGDOM I HJERNEN

DEMENS DATA:

VIS HENSYN OVER FOR DEMENTE

SÅDAN VISER DU HENSYN

Leaflet designed for Danish secondary school children

ii. Encourage early diagnosis and treatment

Early diagnosis of dementia is critical as it may allow families to adapt to the presence of Alzheimer's disease in their family and plan for the future. At this stage the person with dementia can be fully involved in decision-making, and future planning can be a collaborative effort. Early diagnosis gives people with dementia and their families time to find the care options that work for them. It may also help prevent crises and facilitate adjustments to unexpected behaviours (Woods et al, 2003). Importantly, early access to treatments may also slow the progression of symptoms and protect quality of life of the patient.

Delaying the diagnosis leads to missed opportunities, the person with dementia may inevitably be excluded from the major decisions about his or her future, and a gulf of silence may develop within the family. The family carers are left making decisions at crisis points.

A startling fact is that it takes on *average* 1.5 years from the presentation of first symptoms of Alzheimer's disease to confirmation of diagnosis of dementia (Facing Dementia Survey, 2004). **1.5 years on average to achieve diagnosis means families go through 1.5 years of often unexplained behaviour, fear, frustration, desperation, disbelief and anger.**

Delays in diagnosis are the compound effect of several factors:

i) *Older people themselves* may dismiss the signs of early Alzheimer's disease (memory loss, confusion, etc) as natural signs of ageing.

ii) *Family members* may also dismiss symptoms as signs of normal ageing. They may also be in denial that their loved one could have Alzheimer's disease. In fact, denial is thought to account for up to 60% of delays in diagnosis (Facing Dementia Survey, 2004).

iii) *Professionals are often reluctant* to diagnose Alzheimer's disease. They may lack the training to diagnose Alzheimer's disease early. They may fear giving the label of Alzheimer's disease to a patient. Or they may dismiss symptoms of Alzheimer's disease as being part of the natural ageing process.

> *"Early detection is important – especially with treatments now available.*
> *It is also important to protect relationships. I am ashamed of the times*
> *I felt frustrated or impatient before knowing what M's disease was."*
> – Brenda, carer

iii. Better training of all care staff

Physicians' attitudes may have a huge impact, positive or negative, on the way a diagnosis is made, communicated and taken on board by families. Experts speak of a 'critical treatment window' during which real changes may be made for the patient's benefit – and yet many physicians do not subscribe to this view and adopt a somewhat nihilistic attitude towards treating Alzheimer's disease [3].

Many physicians may actually not be aware of treatment options available for dementia and may lack specific training on dementia (Facing Dementia Survey, 2004). This lack of training is not only true of family doctors. **All those who are the first point of contact for older people in the community and in hospitals need to be more aware of the signs, symptoms and implications of Alzheimer's disease.** This includes a wide range of doctors, nurses, home care staff, social workers and community services staff. And exactly the same applies to all those professionals who have contact with people with dementia during the long course of the illness. It is not sufficient for there to be a group of professionals with specialist knowledge of dementia in specialist dementia services; those in generic services for older people, in care homes and general hospitals and in general community services also need this knowledge.

In the Czech Republic, the Alzheimer's Association invites medical and social care students into a daycare centre to participate in social and light care activities with Alzheimer's patients. The scheme allows students to gain experience of working with people with dementia at the early stages of their training.

iv. Flexible support services for families

To allow families to care for loved ones within their home, **care packages need to be flexible enough to accommodate the chosen care patterns of each family context.** People with dementia and their families should be able to choose the combination of services that works best for them, whether it be counselling, information services, a helpline, or respite care, without having to incur out-of-pocket costs.

Continuity of care is also critical for the wellbeing of both the carer and the person with dementia. One carer spoke of the difficulties of going through 14 carers in 8 months *(B Pointon, personal communication).* **Services need to support care workers and provide incentives to remain in the sector.**

It is important that care packages support the independence of the person with Alzheimer's disease and provide support and respite to family members to ensure that they can cope (Poole T, 2006). Yet **typically, care does not come in a 'package'.** Care is provided by a multitude of agencies which do not have a single coordinator working across them. **It thus becomes the responsibility of the carer to coordinate care across different agencies, organisations and bureaucracies.**

> *"For all services, the patient and carer must be put at the centre of thinking – to allow the design of imaginative, individualised care programmes around their needs. And most importantly, we need to abolish the artificial divide between health and social care. Care is care is care."* – Barbara, carer

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[3] Wilkinson et al, 2005.

v. Regular respite care for carers

Caring for a relative affected by dementia can be absolutely exhausting. In the UK alone, informal carers supporting people with all conditions save the government *€84 billion (£58 billion) per year.* They provide a service that our health and social care services currently do not have the capacity to cope with. As was stated by one carer:

> *"Free respite as a right, and not just at times of crisis, planned on a regular basis, is the least we should be given in return for the care we are giving for free. We will carry on caring at home, however demanding it is, for as long as we can, but only with the right level of personal support."* – Kate, carer

Respite care is as important in the home as outside the home. The patient may reach a stage where it is too difficult or disruptive to move him or her from the home setting – thus **respite is needed in the home by a trusted carer,** and some people at earlier stages of the illness prefer people visiting them at home rather than having to go out to a day centre or into a care home. Continuity of care is again essential, to ensure that the patient feels safe and secure whilst the carer takes a needed break.

'Granny sitting'

A successful respite care scheme in Prague

The Czech Alzheimer Society created a respite scheme that helps carers and provides training to respite care students. The scheme was successful in receiving funds from the municipal government, partly because organisers assembled a detailed evidence-based argument on the known benefits of respite initiatives in postponing eventual institutionalisation and reducing stress and illness amongst carers.

Respite carers typically provide a whole day's coverage to a person with dementia, allowing the family carers to pursue their own activities.

The programme currently involves 30 students from a local academy for healthcare professionals and is considered to be a great success. On the one hand, primary carers report significant improvements in health and overall quality of life. On the other hand, the students report a real benefit in understanding the impact of the disease on an individual and their family. They are treated as paid employees and receive a useful supplement to their income whilst studying. Most participants report feeling like 'part of the family' within a short period of time.

vi. Provide a welcome environment in care homes and in the community for all family members

Care homes can be forbidding environments to families, making it difficult for them to maintain close contact with their relatives once they are living in a home. Care homes should be encouraged to create family activity rooms to allow closer contact between the residents and younger generations. Simple steps can be taken to make the whole family feel welcome in care settings, for example by providing games, books and toys for children visiting their grandparents. Working on life history books, photograph collections and other personal reminiscence projects can very usefully involve the person with dementia, the wider family and staff members.

A successful example of this in the community is the 'Alzheimer's Café' which has now been adopted in Belgium, the Netherlands, Denmark and other countries.

The Copenhagen Alzheimer's Café

A welcome venue for the whole family

Following the example of the Dutch Alzheimer's Association, the Danish Alzheimer's Association set up a number of Alzheimer Cafés. The Cafés provide an opportunity for people with Alzheimer's disease and their families to meet others in a similar situation and take part in group activities in an informal and welcoming setting.

Meetings are usually held in a function room at a local care centre, although most people come from all over the neighbourhood.

Group activities include singing songs and reciting poems, many of which are chosen to remind the people with dementia of their childhood schooling. Other activities include reminiscence and telling personal stories.

Grandchildren are welcome and are included in activities whenever possible. Children are encouraged to play and be active rather than simply 'sitting still'. If a person with dementia dies, their families are encouraged to continue to participate in the group as volunteers.

The Café schedule and activities are advertised on the internet and attract around 50 to 60 people each time.

vii. Involve younger people in delivering services to people with dementia in care homes and community services

Well managed joint activities that bring people with dementia in contact with children or younger people have been shown to provide a great deal of mental and physical stimulation to people with dementia. They may promote visible, immediate improvements in both mood and responsiveness to stimuli. **Very often, the benefits of this joint activity continue even after the activities are concluded.**

Engaging younger people in practical activities, such as art, craft, music and drama, can be a sure way of helping age interaction work in a 'fun' environment which is satisfying for all involved.

The graduate students volunteer scheme – Malta

Since August 2005, the Malta Dementia Society has run an initiative designed to encourage recently graduated students to become involved in dementia care. After training, the students are invited to befriend people with dementia in a nursing care setting. The aim is to help people with dementia interact more during the day and to introduce an active daily routine on the wards. The students are encouraged to co-ordinate activities with each other and work in groups, for example, playing card games, reading of newspapers and talking to people with dementia.

The initiative has met with considerable success. Participants are given a certificate to feature on their CV, giving them something back for their efforts. In addition, organisers feel the scheme has set an example of good practice to the rest of the hospital staff and is improving attitudes and standards of care.

The Malta Dementia Society is also developing an Activity Centre that will provide day care for people with dementia, both in the community and in long-term stay nursing homes. The Society currently plans to extend the student volunteer scheme to the centre when it opens in 2007.

Participants in the Malta Dementia Society's summer volunteer programme read a religious leaflet to a patient.
– Malta Dementia Society, 2006

Maltese students participate in a 'Memory Walk', an awareness-raising activity.
– Malta Dementia Society, 2006

"I played cards, gave hand massages, played easy geographical quizzes and read short stories mostly related to Maltese Folklore and culture. Reading short stories seemed to work best as most of the patients could relate these stories to their past, making it easy for them to start a conversation."
– Student volunteer, Malta

"I used many different activities when interacting with clients. For those able to talk and with good hearing I enjoyed reading out magazine articles, praying, chatting about their families, and watching TV. I helped to get them talking by looking at postcards of Malta I brought with me. I also brought my own stereo so we could listen to music. I think the CDs they most enjoyed were the ones with opera and Italian songs! In the case of clients who had problems in communicating, bad eyesight and hearing, I would usually give the client a hand massage with massage oils."
– Student volunteer, Malta

"At the end before I left I could see a big smile on her face. This made me realise how helpful we can all be by just dedicating some of our time talking to the elderly, by just offering our presence and patience."
– Student volunteer, Malta

Age interaction at work through music The 'Dragonfly Club' music and education evenings in the Czech Republic

The Czech Alzheimer Society organises regular concerts in schools for people with dementia and their families. The music is performed by school children who volunteer from a number of schools.

So far, the group has played at around 30 schools in the last four years. As the event provides entertainment and a chance to socialise with others, other people less affected by dementia also tend to come along, for example, family and friends of the volunteer school children.

Because of the close groupings of families often found around primary schools, the concerts provide a good opportunity to educate local communities on dementia. Volunteers hand out leaflets and information packs to the audience. Fund raising is also part of the activity and helps to keep the initiative self-sufficient.

viii. Innovative partnerships that bring the generations together

Youth and old age: a difficult partnership?

Within the context of the family, intergenerational contact with people with dementia is largely invisible as it may be taken for granted as part of ordinary family life.

At a societal level, however, partnerships between young and old do not always come readily. Youth institutions such as schools or clubs are often organised, funded and regulated very separately from those catering for older people. There is enormous potential for more formal pairings between these two ends of the age spectrum. When a person with dementia visits his or her old school, the reminiscence experience may be highly rewarding, but the educational experience for the children can also be of great value for the older person's recollections of the school are likely to be quite vivid. The lesson for the children, that people with dementia can make a very positive contribution, is easily and effectively learned.

Innovative schemes typically rely on a leading 'champion' who can help dispel fears and convince both parties of the benefits of the partnership. It is critical to establish trust between both parties involved and overcome negative perceptions of either the people with dementia or the young people involved.

Some successful intergenerational 'pairings' are described opposite.

"The children adopted the users as their surrogate grandparents, and this helped to improve the relationship with their own relatives. One of the children asked to spend her birthday with the care centre users."
– Patrícia Paquete, Alzheimer Portugal

A child plays games with an older person
with dementia at the Alzheimer Portugal day care centre.

Kindergarten and dementia day care centre join forces – Portugal

Alzheimer Portugal has been running a weekly link up between participants at a dementia day centre and a local primary school since 2006. Every Wednesday, the children come to the centre to play with 'os avós' (the grandparents), as the children call them. Carers feel that the interaction is beneficial for both age groups, but brings particular benefits in psycho-motor stimulation, verbal and non-verbal communication and the expression of affection for centre attendees with dementia.

The centre has also teamed with the primary school to organise local events, including a sports day for grandparents and grandchildren from the neighbourhood. In 2006, young and old held a joint party with activities to celebrate grandfathers' day and raise money for an awareness campaign.

Parents, children and people with dementia
taking part in activities together.

"The positive effect of the children in the care environment is clear. The service users tend to become more animated, making gestures and trying to talk to the children. They smile much more than during activities with only other adults. Occasionally they might react with seemingly strange behaviour like crying or reaching out to grasp the children, but the children seem to understand and not be afraid."
– Care manager

‘Numero’ card game: stimulating children, adults and people with dementia – Australia

Numero is a card game invented by Rev. Frank Drysdale after he was diagnosed with Alzheimer’s disease in 1989. Frank made a deliberate effort to stay mentally fit by playing games and other mental activities, which he often did with his young grandchildren. As a result of these games, he invented ‘Numero’, which has been immensely popular since its first demonstration in 1993 at the Mathematics Association of Western Australia annual conference.

As well as being a worldwide success amongst dementia care groups, the educational community has found Numero useful for teaching mathematical awareness amongst students of all ages. The game therefore is an interesting example of an initiative which has benefits for both younger people and for people with dementia.

Social inclusion meets intergenerational exchange in dementia

The Bungalow, Rugby Mind, England

The Bungalow Centre provides day care to a number of older people, the majority of whom show some degree of dementia. In 2001, the Centre began a scheme offering young men who had earned day leave from a local young offenders' institution the chance to gain work experience in a dementia day care setting [4]. The volunteers participated in largely social and companionship activities, although in successful pairings there were also examples of more personal care interactions.

The success of the scheme overcame initial scepticism and brought real advantages to both groups. The volunteers were offered a chance to engage constructively in the local community and leave the scheme with work experience and an employment reference. Many stayed in touch with the centre upon full release and some moved onto careers in dementia care. Volunteers reported a much closer understanding of their own grandparents or older family friends, especially those with dementia.

On the other hand, the people with dementia were given the chance to mix with the younger generation in a managed environment. The respect and assistance of the volunteers was seen to be enormously stimulating and helped to raise self-esteem.

Despite the perceived success of the scheme at the Bungalow it has been discontinued, underlining the fragility of such innovative partnerships, the lack of funding for such schemes and the importance of individuals prepared to act as local champions.

"The vitality and enthusiasm of the young men was much enjoyed by the members with dementia, many of whom have limited social circles. It reminded them of their own youth, which sparked off many reminiscence discussions. The respect shown by the young men helped them appreciate their own maturity and experience. Many of the members suffer feelings of worthlessness and low self-esteem as a result of the personal challenges of dementia. Yet the help offered by the volunteers in participating, enjoying and being successful in activities was a great boost to them.

On the other hand, I believe the experience greatly built up the self-esteem of the volunteers. The older people reciprocated the respect and acceptance they received. The volunteers from the young offenders institution were accepted as normal members of staff alongside paid staff and other youth volunteers, offering them a positive way to engage in a team." – Ms Fiona Palmer, Manager, The Bungalow Centre

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[4] The scheme featured as a case study in: Gillian Granville and John Laidlaw, 2001. *A Partnership of Trust: Young Offenders supporting older people in care settings. An example of social inclusion through intergenerational practice.* Centre for Intergenerational Practice, The Beth Johnson Foundation, Stoke on Trent

5

Conclusions and recommendations

There are currently 5.5 million adults living with dementia in Europe. Alongside these individuals are the millions of spouses, partners, children, siblings and grandchildren who must learn to adapt and cope with the changes in their loved one, provide care and support, and weave their way through a labyrinth of services to ensure that the quality of life of their loved one and of their whole family is protected.

We owe it to those families affected by dementia, and to ourselves as an ageing society, to raise awareness and understanding of dementia across all sectors of society and across all generations. As devastating as the condition may be, we can do a lot to improve the situation of people affected by dementia and help families cope. There are of course many difficult and distressing aspects to the care of a loved one with dementia, but well devised and planned care can be exceptionally rewarding.

Specifically, we would urge the following ***Calls to Action:***

Within our communities, we must ensure that:

- Families are offered comprehensive, individualised support services
- Families have regular, free respite when and where they need it
- Support services, such as counselling, are offered to the entire family
- Care homes provide the best care possible to individuals with dementia but also provide a welcome environment for families.

We urge policymakers to:

- Develop comprehensive policies and plans for addressing the health and social needs of people affected by dementia
- Allocate sufficient resources to ensure that better services, better support and better care is made available to all families affected by dementia.

And finally, we urge all generations within our societies to:

- Seek out innovative partnerships that bring younger people in contact with people with dementia, encouraging them to help bring them out of their isolation and foster their social inclusion
- Educate ourselves about dementia and its impact on those affected.

Finally, it is **essential** to recognise that better understanding must begin with empathy. Dementia is not ‘their problem’, it is ‘our problem’. All of us need to take responsibility and ownership for dementia as a part of our ageing societies. This includes governments, policymakers, the media, health and social care professionals, and ordinary citizens.

References

Alzheimer Society 2007. Dementia UK. A report into the prevalence and cost of dementia. Available on: http://www.alzheimers.org.uk/News_and_Campaigns/Campaigning/PDF/Dementia_UK_Full_Report.pdf.

Comas-Herrera A, Wittenberg R, Pickard L, Knapp M (2003). Cognitive impairment in older people: its implications for future demand for services and costs. PSSRU discussion paper no 1728. London: Alzheimer's Research Trust.

Godfrey M, Surr C, Townsend J, Boyle G, Brooker D (2005). *Prevention and Service provision: mental health problems in later life.* Commissioned by Age Concern and the Mental Health Foundation. Leeds and Bradford: Institute of Health Sciences and Public Health Research, University of Leeds and Division of Dementia Studies, University of Bradford.

Iliffe S, De Lepeleire J, Hout van H, Keeny G, Lewis A, Vernooij-Dassen MJFJ. Understanding obstacles to the recognition of and response to dementia in different countries: a modified focus group approach using multinational, multi-disciplinary expert groups. *Aging Men Health* 2005; 9(1): 1-6.

Langa K, Chernew M, Kabeto M, Herzog A, Ofstedal M, Willis R, Wallace R, Mucha L, Straus W, Fendrick A (2001). National estimates of the quantity and cost of informal caregiving for the elderly with dementia. J Gen Int Medicine 2001; 16(11): 770-8.

Phillipp-Metzen, Heike Elizabeth (2006). Grandchildren of persons with dementia: do their caring experiences affect their willingness to provide care in the future? Report to 22nd Conference of Alzheimer's Disease International, Berlin, October 2006.

Poole, T. Dementia Care. Wanless social care review. Kings Fund 2006. www.kingsfund.org.uk/publications.

Sartorius N. Introduction: stigma and discrimination against older people with mental disorders. *International Journal of Geriatric Psychiatry* 2003; 18(8): 669.

Vernooij-Dassen MJFJ, Moniz-Cook ED, Woods RT, De Lepeleire J, et al. Factors affecting timely recognition and diagnosis of Alzheimer's disease across Europe: from awareness to stigma. *International Journal of Geriatric Psychiatry* 2005; 20: 377-386.

Woods RT, Moniz-Cook ED, Ilifee S, et al. Alzheimer's disease: issues in early recognition and intervention in primary care. *Journal of Royal Society of Medicine* 2003; 96 (7): 320-324.

Appendix 1 –

Selected literature and reference materials that promote intergenerational learning on dementia

UK

Doeg, Rachael, 'Telling the children' 2005, (p. 10), **National Newsletter of the Alzheimer's Society,** November 2005

Duckworth, Susan, 'Awareness through art', pp 5-6, **Signpost** (Vol 10 (2), Oct 2005

Langston, Laura; Gardiner, Lindsey, 'Mile-high apple pie', The Bodley Head, 2004 ISBN 0370327365

Alzheimer's Society; Jordan, Penny (Producer), 'About my grandfather, about my grandmother: children and young people talk about how they have been affected by dementia within the family', Alzheimer's Society (video), 2004 (www.alzheimers.org.uk)

McGuigan, Jim, 'Need to know Alzheimer's disease', Heinemann, 2004 (www.heinemann.co.uk/library) (ISBN 0750674709)

Mayo, Sue, 'A little bit of magic', 2004, pp 10-12, **Nursing Older People** (Vol 16 (3)

Ironside, Virginia; Sharratt, Nick (illustrator), 'The wise mouse', Young Minds, 2003 (www.youngminds.org.uk);

Dutton, Jean, 'What's the learning?', 2004, Jean Dutton (Alzheimer's Society Huddersfield Branch, First Floor, 12 St Georges Square, Huddersfield HD1 1JF, UK Telephone +44 (0)1924 490258)

Lowton, Karen, 'Supporting bereaved students in primary and secondary schools', National Council for Hospice and Specialist Palliative Care, 2004 (National Council for Hospice and Specialist Palliative Care Services, First floor, 34-44 Britannia Street, London WC1X 9JG, UK Tel: +44 (0)207520 8299) (ISBN 1898915342)

Woodhead, Hilary, 'Mind the generation gap' 2004, pp 12-13, ***Journal of Dementia Care***, Vol 12 (2)

Cowley, Kim, 'A small scale survey looking at young people's perceptions of dementia', Kim Cowley, 2003, (Alzheimer's Society Norwich and District Branch, 9 Valentine Street, Norwich, Norfolk NR2 4BA, UK Tel: +44 (0)1603 763857)

Wild, Margaret; Huxley, Dee, 'Remember me', 1990, Puffin Books, Penguin Books ltd. ISBN 0140505865

Leeds Animation Workshop, 'Grief in the family', 2002, video (Concord Video and Film Council Ltd, Rosehill Centre, 22 Hines Road, Ipswich, Suffolk IP3 9BG, UK)

Berenbaum, Rakel, 'I like when you kids come' – an intergenerational club, 2002, pp 10-11, ***Journal of Dementia Care***, Vol 10 (6)

Hughes, FM, 'The girl on the shore: adventures at Beacon House – a care home with a difference', Jessica Kingsley Publishers, 2003, (www.jkp.com), ISBN 1843101114

Burgess, Melvin, 'The ghost behind the wall', Andersen Press, 2000, (Andersen Press, 20 Vauxhall Bridge Road, London SW1V 2SA, UK), ISBN 0862644925

Shawver, Margaret, 'What's wrong with grandma? A family's experience with Alzheimer's', Prometheus books (UK), 1996, ISBN 1573921076

Health Education Board for Scotland, 'Understanding dementia: a guide for young carers', Health Education Board for Scotland, 1996, ISBN 1873452861

Cargill, Kristi, 'Nana's new home: a comforting story explaining Alzheimer's disease to children', Krisper Publications (UK), 1997, ISBN 0966056604

Hann, Lizi, 'The Milk's in the Oven', The Mental Health Foundation, 1998, (www.mentalhealth.org.uk)

Gilliard, J, 'Ripples of stress across the generations', 1996, pp 16-17, ***Journal of Dementia Care***, Vol 4 (4)

Gilliard, Jane, 'The long and winding road: a young person's guide to dementia', Wrightson Biomedical Publishing Ltd (UK), 1995, ISBN 1871816319

Alzheimer's Society (UK), Factsheet 'Explaining to Children' (www.alzheimers.org.uk/caring_for_someone_with_dementia/relationships/advice_children.htm)

Manthorpe, Jill, 'A Child's Eye View: Dementia in Children's Literature', ***British Journal of Social Work***, Vol 35, No. 3, April 2005, pp. 305-320, Oxford University Press

Alzheimer's Society, 'What's going on in Grandad's head?', interactive factsheet, http://www.alzheimers.org.uk/News_and_campaigns/Alzheimers_Awareness_Week/grandadshead.htm

Alzheimer's Society, 'Understanding Dementia', interactive factsheet, http://www.alzheimers.org.uk/News_and_Campaigns/Alzheimers_Awareness_Week/understandingdementia.htm

USA

Shriver, Maria, 'What's happening to grandpa?' Little, Brown, and Company and Warner Books, 2004 (ISBN 0316001015)

Guthrie, Donna, 'Grandpa doesn't know it's me', Human Sciences Press Inc (USA), 1986, ISBN 0898853087

Bauer, Marion Dane, 'An early winter', Clarion Books, 1999, ISBN 03953903726

Churchill Media, 'Just for the summer', Churchill Media, 1990, video, (www.terranova.org)

Canada

Interactive game (Canada), http://www.alzheimer.sk.ca/english/Just4Kids/

Australia

Hawke, Rosanne, 'A kiss in every wave', Lothian Books, 2001, (www.lothian.com.au), ISBN 0734402678

Stevenson, Laura C, 'All the King's horses', Corgi Books, 2001, ISBN 0552547182

Angell, Barb, 'Poppy's head', Angell Productions Pty Limited (Aust), 1999, video

The Ribbon Online (provides information for caregivers dealing with Alzheimer's and Dementia), http://www.theribbon.com/articles/teeninfo.asp

Europe

Alzheimer Europe, 'Cheri mamie (Dear grandma)', Alzheimer Europe, 1999, http://www.alzheimer-europe.org, (French, German, Italian, Greek, Flemish and Danish). An English version is also produced by The Alzheimer Society of Ireland (www.alzheimer.ie).

Mogensen, IF, 'Why won't you answer me Grandpa?', 1997, (Inga Friis Mogensen, Kirkesovel 3. Nr. Soby, DK-5792 Arslev, Denmark), ISBN 8798574736

Czech Alzheimer Society (supporting literature):

Prava pacientu
CALS – Strucna informace o nas
O modifikaci domaciho postredi
Tipy pro dobrou komunikaci
Struktura kazdodennich cinnosti
Obecna informace o demencich
Co byste meli vedet a udelat jestlize mate AN
Deset priznaku AN
Alzheimerova nemoc mozne aktivity
Obtize s polykanim – caste a opominjene
Jak mam zvladnout peci o nemocneho
Dopis CALS detem
Rychly skrinink demence
Jak pecovat na dalku
Alzheimerova choroba – algorytmus 2005
Deset tipu jak pomoci rodine
Kydz AN zacne brzo
Svetova zprava o zdravi 2001
Na pomoc pecujicim 2001
Evropska charta pacientu senioru-revize
Jak rici rodine a pratelum ze Vas blizky ma AN
Alzheimer Europe – Charta pacientu a pecovatelu
Informace pro dospivajici
Jak pecovat o nemocneho v pokrocilem stadiu AN
Zeny a AN 2005
10 Priznaku stresu pecujiciha a 10 rad
Jde o Alzheimerovu chorobu?
Dopis o spatnem zachazeni se seniory 2005
Rizikove faktory demence
Normotenzni hydrocefalus
Frontotemporalni demence
Dopis o hypersexualite souvisejici demenci
Mirna kognitivni porucha
Alzheimer – jak si poradit
Denni centra
Podpurne skupiny
Jak lepe pecovat (J. Zgola)

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About us

ILC-UK (www.ilcuk.org.uk)

The International Longevity Centre (ILC-UK) is an independent think-tank influencing policy on societal ageing and population change. The ILC-UK develops ideas, undertakes research and creates a forum for debate and action.

ILC-UK events include seminars, presentations, conferences and workshops. These aim to bring together decision-makers, planners, policymakers and innovators by organising events around the key themes of longevity, societal ageing, the future of older people, demographic change and life-course planning.

Alliance for Health and the Future (www.healthandfuture.org)

The Alliance for Health & the Future is a 'think-and-do tank' established to identify, inform and raise awareness of behaviours and systems that can lead to greater well-being and productivity throughout life. The Alliance conducts scientific research and investigations, hosts events for scholars and thought leaders and carries out extensive education and outreach.

Alzheimer Europe (www.alzheimer-europe.org)

Alzheimer Europe (AE) is a non-profit organisation, which aims to improve the care and treatment of Alzheimer patients through intensified collaboration between its member associations.

The majority of people with dementia live at home and are cared for by their relatives and friends. Although many organisations are active in supporting them, carers often work alone and lack the know-how and inspiration which could be given by others. AE thus hopes, through its activities, to answer a growing need in society, and especially among the community of people affected by the existence of the disease. The exchange of experience and knowledge as well as collaboration on new approaches will stimulate and motivate people with dementia. Further to this, it will ensure that information on best practice in the care of Alzheimer sufferers is available throughout Europe and beyond.

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