

# **Coping with Alzheimer's and other related diseases – improving patient care at home: How to cope (non-pharmacologically) with crisis situations (behavioural disorders) occurring in patients' home**

Discussion paper

**Murna Downs**  
Bradford University

## **Overview**

It has been estimated that there are about 6.1 million people with dementia in the 27 Member States of the EU (Alzheimer Europe, 2006, 2007 cited by Georges et al., 2008). Ferri et al (2005) predict that these numbers will double by 2040. Most people with dementia live with their families in the community, thus at least doubling the number of people affected by dementia (Georges et al., 2008). Care for people with dementia is now a public health priority in much of Western Europe with several European countries having national strategies for dementia. These strategies recognise the need to support family carers as the people who provide the bulk of care to people with dementia.

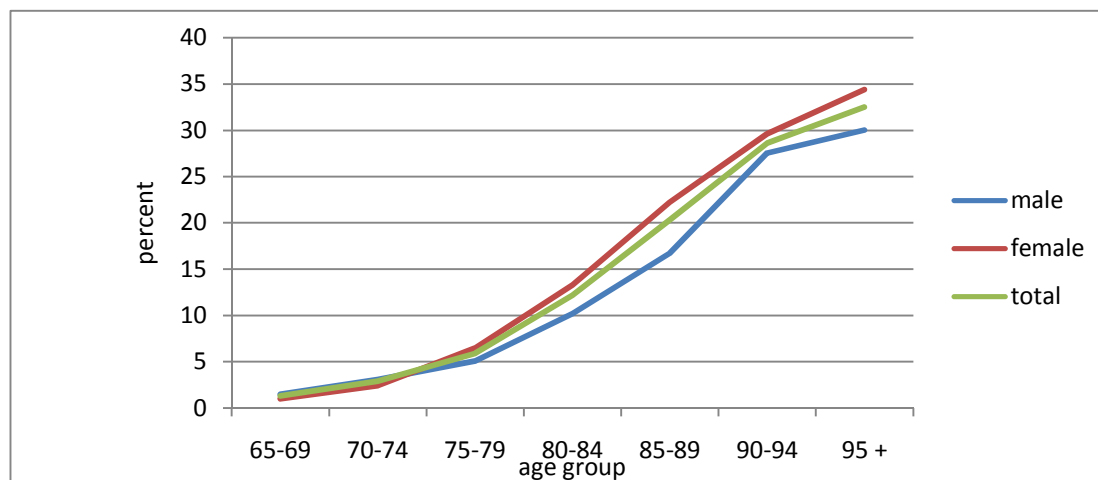
While caring for a relative with dementia may yield many rewards (Nolan et al., 1996), for many families care of a relative with dementia is demanding and is associated with poor mental and physical health. Correlates for carer ill-health include impaired functional ability and behaviours which distress the person and/or the carer. Behavioural changes that carers find particularly difficult to cope with are a risk factor for admission to long term care.

The first part of the paper describes the demographic and policy context. The second part of the paper describes living with dementia including active coping and behavioural aspects. The third part of the paper focuses on family care, with particular emphasis on how families cope with functional changes and behavioural aspects of Alzheimer's disease. The fourth part of the paper discusses the support that is provided to family carers. The final section presents key questions for discussion at the review meeting.

### **1. Demographic and policy context**

It has been estimated that there are about 6.1 million people with dementia in the 27 Member States of the EU (Alzheimer Europe, 2006, 2007 cited by Georges et al., 2008). Ferri et al (2005) predict that these numbers will double by 2040. There are slightly higher percentages of women with dementia in the over 75 years age group.

### Estimates of the population prevalence (percent) of people with late-onset dementia by age group



Source: Knapp and Prince, 2007

Care for people with dementia is now a government and public health priority in much of Western Europe. Several European countries (eg France, England, Scotland, Norway) have national strategies for dementia. Two recommendations common to these strategies are to keep people in their own homes for as long as possible and to provide support to families to do this (OECD 2002, p. 20).

These policies are justified on a variety of grounds including the refrain that most people with dementia want to (and do) live at home with family carers who in turn want to care for them. Throughout Europe most people with dementia are cared for in their own homes by family members. As such the largest public health issue of our time is largely falling to family carers. There is some variation in the balance between family and formal care throughout Europe. For example, Germany and Italy have higher percentages of people with dementia living at home than France or the UK (Bosanquet et al., 1997). In Sweden it is estimated that the ratio between formal and informal care is 4:1 (OECD, 2004).

#### Balance between family and institutional care

Country	Percent living at home
Germany	82%
Italy	80%
France	62%
UK	60%

Source: Bosanquet et al., 1997

Such variation is attributed to demographic differences regarding the size of family and extended family, differences in cultural traditions and expectations re family care and variations in social support systems.

## 2. Living with dementia

### *Active coping with impairment*

The experience of living with dementia includes adapting and accommodating to a neurodegenerative condition which leads to progressive impairment in all areas of mental ability and function, with related changes in behaviour and personality. People with dementia have to adjust to progressive loss of cognitive and functional abilities which increasingly affect familiar occupational and social roles, ultimately leaving the person completely dependent on others. Changes in cognition include changes in memory, information processing, language, judgement and problem solving. Changes in functional ability include changes in instrumental activities of daily living (eg shopping, keeping track of finances) and activities of daily living (eg self care, washing).

We have considerable body of evidence demonstrating that people with dementia actively cope with the cognitive and functional impairments associated with dementia. Clare (2003) in the UK, Sabat (2001) in the US and Phinney and Chesla (2003) in Canada describe the range of ways people with dementia actively cope with cognitive and functional changes. More recently, Sørensen et al (2008) in Denmark describe a range of coping strategies used by people with dementia including adjusting the level at which they participate in activities and in interactions with others. Similarly Phinney (2008) describes how dementia affects the person in terms of its effect on their ability to take part in activities and their loss of social connectedness. These difficulties in turn affect how people feel about themselves including lowering their self confidence and self esteem. Phinney (2008) usefully summarises the range of approaches people with dementia use to cope with, and adapt to, these changes.

#### **Approaches people with dementia use to cope with, and adapt to, cognitive and functional changes**

##### Active strategies

- Work harder
- Reduce demands
- Avoid challenging situations
- Seek and accept help
- Stay active

##### Emotion-focused strategies

- Minimize difficulties
- Keep a positive outlook

Source: Phinney, 2008.

### *Behavioural aspects of dementia*

One of the debates within the field of dementia is the relative contribution of biological, psychological and social factors in the aetiology of behavioural aspects. It is now widely recognised that the behavioural aspects of dementia are more likely the result of interplay between underlying neurological, physical (eg pain), psychological and social factors, in particular the extent and nature of interactions (Kitwood, 1997, Ragneskog et al 2001, Stokes, 2000).

Psychosocial approaches recognise that behaviour is not uni-casual but has multiple interacting causes and different reasons why, and different contexts in which, it is seen as a problem (Bird, 2005). Thus the same behaviour may have different causes in different people and may be viewed differently by different carers (Bird, 2005). The situated-ness and social construction of behavioural aspects of dementia are best captured by Moniz-Cook et al., (2009, p.2) who describes these behaviours as challenging because they 'challenge the norms and rules of the contexts within which they occur'.

Along with Norberg (1996) and Kitwood (1997), Sabat (2001) emphasises that people with dementia continue to strive to find meaning in what is happening around them and their behaviour in any given situation arises from what it means to them. To respond helpfully to what people are communicating through their behaviour, it is necessary to strive to understand their meaning-making and their understanding of the world around them (Norberg, 1996). Invariably understanding a person's behaviour requires us to take their perspective and to engage with their subjective experience (Kitwood, 1997). Empathy with their perspective helps us to understand what the person is trying to communicate and achieve by their behaviour. Psychosocial approaches to understanding behaviour see it as:

- An attempt to communicate or meet need
- A result of a too demanding or insufficiently demanding environment
- A rational response to an untenable situation

*Behaviour as an attempt to communicate or meet need*

Algase et al (1996) and Stokes (2000) argue that behaviours which others find challenging are often attempts to communicate or meet physical or psychological needs. The Need-Driven Dementia-Compromised Behaviors (NDB) Model views 'problem' behaviours as an expression of one or more unmet needs — physical, psychological, emotional or social. It is built on the premise that people with dementia may be unable to conceptualise in thought, or express in language, their needs. This results in unmet needs which are expressed as behaviours labelled by others as wandering, disruptive vocalizations; agitation and aggression; sleep disturbance and resistance to personal care. More recently Cohen-Mansfield (2008) has demonstrated the link between people's behaviour and their need to retain and maintain identity.

**Need-driven dementia-compromised behaviour (NDB)**

Disruptive, agitated, and aggressive behaviours often result from one or more unmet needs — physical, psychological, emotional or social.

Loss of ability to express needs in language causes the person to "communicate" through behaviour.

NDB Model emphasizes the interaction between stable individual characteristics and fluctuating environmental factors that may cause stress or discomfort.

Assessment is the key to accurate interventions and quality of care

Source: Algase et al., 1996

*Behaviour as a result of a too demanding or insufficiently demanding environment*

For others distressed and distressing behaviours are the outcome of the environment placing too great or too little demands on the capabilities of the individual to meet those demands. In the US Lawton (1994) explained behavioural problems as the result of a mismatch between the person and the environment. They argued that where demand exceeds competence to deal with the demand then behavioural excesses, such as aggression, emerge. Where there is insufficient demand from the environment this too leads to distress which takes the form of passivity, depression and withdrawal.

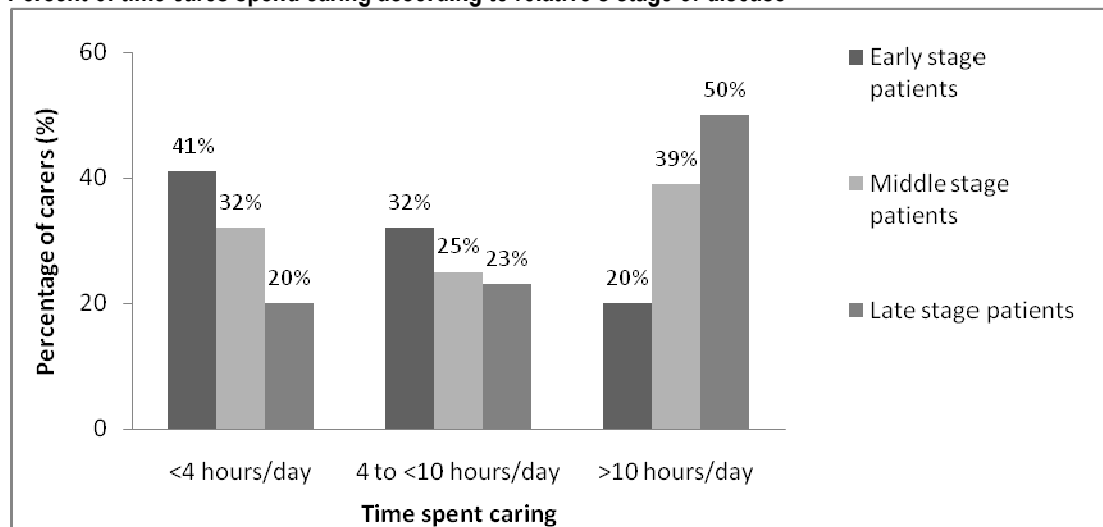
*A rational response to an untenable situation*

As the person with dementia is a human being with feelings, thoughts, expectations and needs (Kitwood, 1997, Skovdahl et al., 2003, Woods, 2001), the cognitive and functional losses often have emotional consequences including frustration, embarrassment and anger (Cheston and Bender, 1999). As a result, many people with dementia engage in behaviour which they or those around them find distressing and challenging (NICE/SCIE, 2006). As such these 'challenging' behaviours are viewed as legitimate responses to an untenable situation. For example, Kitwood (1997) viewed distressed behaviour as a legitimate response to assaults on personhood. More recently Skovdhal and colleagues (2003) describe behavioural aspects of dementia as attempts at protest or defence in the face of a perceived threat. Evidence from care settings by Fossey et al (2006) suggests appropriate engagement with the person with dementia reduces behavioural aspects of dementia and neuroleptic drug use.

### **3. Family care**

*How much time carers spend caring*

Georges et al (2008) surveyed 1000 carers drawn from member organisations in France, Germany, Poland, Spain and Scotland and found that many provided a significant amount of care and that the more impaired their relative, the more time was devoted to caring. Almost a third (32%) of those surveyed spent at least 14 hours a day caring with a further 12% spending between 10 and 14 hours a day caring. Twenty percent of those caring for people with mild dementia spend more than ten hours per day caring for their relative.

**Percent of time cares spend caring according to relative's stage of disease**

Source: Georges et al., 2008

### ***What families care for and cope with***

Carers surveyed reported that their relative was as likely to experience difficulties with activities of daily living, behaviour and communication as with cognition (Georges et al., 2008). Particularly common behaviours included social withdrawal, 'personality changes'<sup>1</sup> and irritability.

**Percent of carers reporting their relative as having the following difficulties**

Difficulty	Percent
Activities of daily living	96
Cognition	93
Behaviour	89
Communication	88

Source: Georges et al., 2008

### ***What carers find most difficult to cope with***

The most challenging stressors faced by carers are the functional changes and behavioural aspects of dementia. Over two thirds of carers found their relatives' difficulties in performing activities of daily living (washing, dressing) the most difficult aspect to deal with while half found behavioural aspects (agitation, aggression) the most difficult aspect (Georges et al., 2008).

**Percent of carers reporting the following difficulties as the most problematic**

Difficulty	Percent
Activities of daily living	68
Cognition	50
Behaviour	45
Communication	36

Source: Georges et al., 2008

Compton et al (1997), in research conducted in Northern Ireland which sought to replicate research conducted in the UK, have demonstrated a link between carers' difficulty coping with behavioural aspects and the potential for abuse of their relative. Spruytte et al (2002) emphasise the importance of preserving the quality of the relationship between the carer and their relative. They conducted semi structured interviews with 144 carers of people with dementia in Belgium and found that changes in their relatives' behaviour and the carers' perception of these changes affected the quality of the relationship. This was more likely to be the case where the spouse was the carer rather than the adult child. It is not always easy to identify whether it is the person's behaviour which leads to carers feeling hostile and critical or whether it is the carers' hostility and criticism which leads to their relative manifesting behaviour that is difficult to manage (de Vugt et al., 2003).

***Effect of caring on carers***

Caring has an enormous impact on carers. Health services and policy makers continue to be accused of ignoring this impact and doing little to prevent or manage the effects of unsupported caring (Georges et al., 2008; OECD, 2004; Twigg and Atkin, 1994; Nolan et al., 1996). Over 30 years ago in the US Zarit and colleagues (Zarit et al., 1985) argued that family carers were the 'hidden victims' of dementia as their needs for support in caring for their relative were often neglected. It has become widely recognised that, in the absence of adequate support, carers are in danger of becoming 'another patient' (Hosaka and Sugiyama, 2003, p.150). Indeed carer distress is one of the reasons relatives are admitted to long term care. While Nolan et al (1996) stress the rewards and opportunities for growth provided by caring, they too stress the importance of the carer receiving adequate support to care.

Carers tend to be spouses or adult children, less commonly other relatives or friends. Adult children tend to be active in the workforce and may have children of their own. Spouses are likely to be elderly themselves with their own age-associated health care needs. As such the impact of caring for a relative with dementia differs whether one is a spouse or adult child (Ankri et al., 2005).

Caring for a relative with dementia affects the carer's well-being in a variety of interrelated ways (Knapp and Prince, 2007) including physically, mentally, socially and financially.

*Physical health* It is now well established in a series of studies conducted in 7 European countries (Belgium, Denmark, France, Germany, Spain, Sweden) (Colvez et al., 2002) and in the US (Ory et al., 1999) that caring for a relative with dementia is associated with poorer physical health. This is especially true for female carers, spouse carers, those from lower socio economic groups (Colvez et al., 2002) and those caring for people whose behaviour is distressing for the person or their relative. It has been established in other fields that exposure to chronic stressors weakens the immune function suggesting that it makes sense to view negative effects on the health of carers as a response to chronic stress.

*Mental health* Caring for a relative with dementia is also associated with compromised mental and emotional health (Ory et al., 1999) with carers particularly likely to develop depression (Cuijpers, 2005). A European study (Colvez et al 2002) of carers in 7 countries (Belgium, Denmark, France, Germany, Spain, Sweden) found that 78% of spouses and 47% of adult children caring for a relative with dementia suffered from depression. Again, these consequences can be thought of as being the result of chronic stress and thus susceptible to amelioration by the availability of support systems and attention paid to carers' perception of the person's behaviour.

*Social support and social consequences* Caring for a relative with dementia ironically also depletes the support systems we all rely in coping with adversity – our social networks. Carers lose familiar aspects of interdependence with their relative at the same time as they experience strained relationships and loss of contact with family and friends. These become especially pronounced with increased levels of impairment (Commissaris et al., 1995). This social (both physical and psychological) distance leaves carers lonely and at risk of isolation which, in itself, is associated with physical and emotional ill-health (Charlesworth et al., 2008). Charlesworth et al (2008) attribute carers' reduced social networks both to stigma and lack of opportunities to socialise. Aneshensel et al (1995) found that two out of three carers in the US reported receiving less practical help than they needed from family and friends.

*Financial resources* Caring for a relative with dementia affects one's financial resources through a variety of mechanisms. Family carers incur additional medical and care costs and those who are adult children or partners of younger people with dementia may lose earning power (Georges et al., 2008).

One of the most common conceptual frameworks applied to understanding carers' experience is the stress process model of Pearlin et al (1990). This model describes primary and secondary stressors. Primary stressors are those related to the person's impairments and include the amount of care needed by their relative. Primary stressors also include the carer's sense of loss of their relationship with the person (Aneshensel et al., 1995). While primary stressors may be similar across families e.g. people with dementia may have similar levels of impairment in self care, the impact of these impairments on carers may differ. Some carers may find dealing with a relative who repeatedly asks the same question overwhelming while others may not find this demanding at all. The key point in this model is that objective measures of primary stressors (eg the severity of impairment) are not strongly associated with carers' level of health and well-being. Instead it is the carer's subjective rating of the impact of these impairments which are related to carer health and well-being. This model opens up the potential for therapeutic intervention with carers such that if one can change the carer's appraisal of the impact of their relative's impairments, then one can interrupt their inevitable association with physical and psychological morbidity (Zarit and Zarit, 2007). The finding that carers respond differently to the same stressor has put the focus of intervention on social support and coping as potential buffers against stressors (Zarit and Zarit, 2007).

#### 4. Support that is provided to family carers

It is widely recognised that carers need a range of supports in order to care for their relative in the community (OECD, 2004, p. 25). Despite these needs for support there is a demonstrated lack of dementia-specific support programmes for informal carers, leading the OECD to conclude as recently as 2004 that the role of informal carer is not valued (OECD, 2004, p.34). Furthermore, for a variety of reasons, families do not always avail of the services that do exist (Georges et al., 2008). Reasons services are not used include lack of privacy, beliefs and attitudes, lack of awareness, lack of acceptability and accessibility and difficulties in service delivery (Morgan et al., 2002). In addition, in some countries, sometimes families are not eligible for the services on offer (OECD, 2004).

Alzheimer Europe list the following as needed: information on dementia, its treatment and support services including the Alzheimer's Societies and the services they provide; access to services and treatments which address behavioural difficulties and functional impairments; flexible and comprehensive services which address changing needs; and appropriate training. They need these supports not as a once off but throughout the course of caring for their relative with dementia (Keady and Nolan, 1995). Despite this, a recent survey of 1000 carers conducted by Alzheimer Europe (Georges et al., 2008) found that only 17% of carers considered the level of care in their country to be good and only 23% felt services were meeting their needs. Clearly there is a significant gap between the policy aim of keeping people at home and nature of support provided to family carers to help them keep their relative at home.

#### **Information about dementia and available services**

Many of the national strategies on dementia emphasise the importance of carers getting timely information and support (see for example Department of Health, 2009). The need for such information across Europe has recently been highlighted (Georges et al., 2008). Concerns were raised at the lack of information provided to family carers, especially regarding the progress of the disease and available supports and services.

**Percent of carers reporting no information was provided**

	<b>Percent</b>
At time of diagnosis	19%
On dementia as a disease	50%
On disease progression	66%
On Alzheimer's Associations	59%
About services available to them	82%

Source: Georges et al., 2008

It is worth noting that carers vary in their needs and preferences for information. Some want to know everything about dementia, even if they find the knowledge distressing, whereas others only want to know what they need to know to get by. Proctor et al (2002) suggest that what carers need is to receive information in combination with emotional support to help them use the information constructively rather than have it overwhelm or depress them.

### ***Training and support in preventing and managing behavioural and functional aspects of dementia***

There is now sufficient evidence to conclude that training family carers leads to positive outcomes both for the family carer and their relative with dementia. There is less evidence to suggest that such programmes are a part of mainstream support provided to carers. Training takes a variety of forms with the best evidence for those programmes that combine training with ongoing support (Mittelman et al 1996, 2004). Increasing emphasis is being given to the role of the carer – inadvertently or not – in the manifestation of behavioural aspects of dementia and optimisation of their relatives' functional abilities (De Vugt et al., 2003). Working with carers to change their cognitions and behaviour can be effective in reducing the salience and/or manifestation of behavioural aspects and in promoting optimal functional ability.

The idea of identifying what people with dementia enjoy doing and finding ways to assist them in engaging in these activities was first recognised as worthy of empirical study by Teri and Logsdon (1991). Recently, Graff et al (2006) have demonstrated that community occupational therapy is an effective psychosocial approach to improving functional ability for people with dementia and improving carers' sense of competence. The intervention is tailored to the needs and aspirations of each person with dementia and their carer. The occupational therapist helps people with dementia and their carers to prioritise activities they want to improve and then helps them to use their skills and resources to meet these goals. The authors have demonstrated how such an individualised intervention is not only effective but also cost effective (Graff et al., 2008).

**Practice example** – Occupational therapy at home

10 one hour sessions over 5 weeks focusing on both person with dementia and carer

Sessions 1-4:

Person with dementia and carer define problem area and identify meaningful activities

Sessions 5-10:

Use compensatory and environmental strategies to improve performance of daily activities

Train family carers using cognitive behavioural interventions to use supervision, problem-solving and coping to sustain their relatives' and their own autonomy and social participation

Source: Graff et al., 2006

Much of the literature regarding preventing and managing behavioural aspects of dementia comes from work with people with dementia living in residential care. These approaches are variously termed person-centred or psychosocial approaches to distinguish them from drug treatments. Bird (2005) advocates that the most effective we can be is in changing carers' attitudes and practices rather than changing what the person with dementia does.

It is self evident that family carers' response to their relatives' behaviour will be affected by the way they conceptualise the behaviour or the attributions they make about its cause. Where family carers attribute what the person is doing as being under their control, they are likely to be more critical of their relative (Spruytte et al., 2002). In his accompanying editorial on Fossey et al (2006) study Andrews (2006) notes that carers need to be able to decipher the meaning and message in people's actions and utterances. Rather than seeing behaviour as meaningless, unpredictable and only treatable with drugs, carers need to seek the meaning and sense in what the person is saying and doing. At least in the nursing home environment, there is evidence to suggest

that training staff in such person-centred approaches to care does provide an effective alternative to drug treatment for behaviour (Fossey et al., 2006), there is no reason we cannot do same with family carers.

For example, Teri et al (2003) in the US trained carers to engage their relative in exercise and use problem solving to manage behaviour. This resulted in decreased depression in carers and increased functioning in people with dementia. In a later study community consultants supported family carers in behaviour management with the result that carers' ability to manage problem behaviour improved over 6 months although the frequency of such behaviour did not change (Teri et al 2005). Moniz-Cook et al (2008) have replicated this work in the UK by training community mental health nurses to support family carers. The intervention incorporated family counselling, behaviour problem solving and functional analysis and led to decreased stress in family carers and behaviour problems.

Innovative approaches to supporting families with information and advice about their relative's behaviour are available in parts of Australia, as part of the government's National Dementia Strategy. Such approaches may well be appropriate in the European context.

Practice example: **Dementia Behaviour Management Advisory Service (DBMAS)**

What dementia related behaviour is

When the thought, mood, speech and or action of the person with dementia presents as a change from their normal behaviour and it affects the quality of their life and / or the lives of those they live and interact with.

"Behaviours are solutions to events in people's lives"

Who we can assist

This service is available to care-workers, services and carers providing care to people with dementia who are seeking or accessing Australian Government funded aged care services, where the behaviour of the person with dementia is impacting on their care including:

staff and volunteers of Australian Government funded aged care services,  
other clinicians (eg GPs, staff of mental health services for older people) and  
family carers.

**How we can assist you**

Our team of health and allied health professionals will provide you with telephone advice and support 24 hours a day. During business hours we can provide a further range of supports to assist you to manage behaviours related to dementia.

"Listen to the behavioural whisper to avoid the behavioural shout"

We will work with a range of other health care professionals to achieve optimal outcomes in behaviour management for people living with dementia and their carers. DBMAS has access to a range of professionals, including: doctors, geriatricians & psycho geriatricians, psychologists, neuropsychologists, physiotherapists, speech pathologists, nutritionists, pharmacists and other specialists.

What does the service provide?

Our team of health professionals will provide clinical assessment, intervention and evaluation of behaviours related to dementia.

**Our vision and goals**

- To improve the quality of life of those with dementia, their families and those who care for them.
- To provide advice, support, information and education to improve knowledge and understanding of the behaviours of dementia.

**Our philosophy:**

All behaviour is a form of communication. We all need to communicate and people with dementia find their own ways though their own unique behaviours.

The Dementia Behaviour Management Advisory Services is here to assist you to understand and manage the behavioural issues caused by dementia.

***Instrumental and practical support****Home help and personal care*

Carers need support for the practical tasks of caring for their relative. This includes home help assistance with the tasks of daily living (housework, shopping) as well as help with the personal care of their relative including washing and dressing. In most European countries these services are not dementia-specific. They are in Germany, the UK and Sweden. In a survey of 1000 carers Alzheimer Europe (Georges et al., 2008) found that only 44% of carers had access to home support and only 30% used it.

*Day care and respite*

Respite and day care were originally developed with a view to providing the family carers with a break from their relative. With the growing recognition of the importance of the person's well being it is now recognised that day care and respite need to also benefit the quality of life of the person with dementia (Schols and van der Schriek-van Meel, 2006). The under use of day care services have been a concern for some time. In a survey of 1000 carers Alzheimer Europe (Georges et al., 2008) found that only 42% of carers had access to day care and only 28% used it. Day care services provide a structured day that helps keeps the person active and constructively engaged. Research evidence from both Sweden (Wimo et al., 1993) and the US (Zarit et al., 1998) suggests positive effects. Zarit et al (1998) found engagement in activities to lead to decreased behavioural aspects of dementia. Innovations in day care compare favourably with more traditional approaches. For example, an innovative day care provided on a small dairy farm in Netherlands suggests decreased behavioural distress and increased engagement in activities for people with dementia (Schols and van der Schriek-van Meel, 2006)

**Practice example – Day care on a dairy farm in Netherlands**

Provides place for 12 people. Those attending have an affinity for dairy farm life. Participate in farming activities. Enjoy life in keeping with former interests. Twice as many men as women in comparison to nursing home day care where ratios are 1:1. No behavioural problems vs 42% in nursing home day care. Family satisfaction higher in dairy farm day care.

Source: Schols and van der Schriek-van Meel, 2006

Many government policies include the provision of respite and short breaks. Respite is a traditionally under used service with carers reporting decreased functioning and quality of life for their relatives who attended the service. Respite is generally provided in a nursing or residential care setting although innovative approaches have also been described. Charlesworth et al (2007), on the basis of research examining social networks and likelihood of using services, suggest that respite might usefully be offered by one's own social networks, particularly for those with private restricted networks. Treolar and colleagues (2001) report on the usefulness of a night time respite service which can be used once or twice a week on a regular basis rather than a once or twice yearly period of two weeks.

### ***Financial support***

In some European countries families receive financial support in a variety of forms. These include: carers' allowance, tax credits, direct financial support (e.g. France, Sweden), national long term care insurance, financial compensation for expenses (e.g. Germany), and caring credits to offset the potential loss of pension (e.g. UK and Germany).

### ***Multi component interventions***

While described separately for the purposes of this report, there is overwhelming evidence that the most effective supports for family carers incorporate elements of practical support with training and emotional support. Such individually developed multi-component interventions including a range of services decrease burden, improve quality of life, and enable carers to care for their relative at home for longer (Mittelman etc).

## **5. Key question for discussion at the meeting**

There is now compelling evidence that we can prevent and minimise much of the distress experienced by carers and people with dementia and improve both people with dementia and carers ability to cope. The key question facing us is how we can implement this evidence such that it constitutes mainstream practice across Europe.

## References

- Algase DL, Beck C, Kolanowski A et al (1996) Need-driven dementia-compromised behaviour: An alternative view of disruptive behavior. *Am J Alzheimers Dis Other Dem*, 11, 10-19.
- Andrews GJ (2006) Managing challenging behaviour in dementia. *BMJ*, 332, 741.
- Aneshensel CS, Pearlin LI, Mullan JT, Zarit SH, Whitlatch C (1995) *Profiles in caregiving: The unexpected career*. New York: Academic Press.
- Ankri J, Andrieu S, Beaufile B, Grand A, Henrard JC (2005) Beyond the global score of the Zarit Burden Interview: useful dimensions for clinicians. *Int J Geriatr Psychiatry*, 20, 254-260.
- Bird M (2005) A predominantly psychosocial approach to behaviour problems in dementia: treating causality. In Burns A, O'Brien J and Ames D (eds) *Dementia 2<sup>nd</sup> edition*, London: Hodder Arnold.
- Bosanquet N, Huttin C, Kurz A et al (1997) Alzheimer's disease: an international perspective on care delivery. *Health Policy Review*, No. 11. London: Imperial College of Science, Technology and Medicine, University of London.
- Charlesworth G, Tzimoula X, Higgs P, Poland F (2007) Social networks, befriending and support for family carers of people with dementia. *Quality in Ageing – Policy, practice and research*, 8(2), 37-44.
- Charlesworth G, Shepstone L, Wilson E, Reynolds S, Mugford M, Price D, Harvey I, Poland F (2008) Befriending carers of people with dementia: randomised controlled trial. *BMJ*, 336(7656), 1295–1297.
- Cheston R, Bender MP (1999) *Understanding dementia*. Philadelphia: Jessica Kingsley Publishers.
- Clare L (2003) Managing threats to self: Awareness in early stage Alzheimer's disease. *Social Science and Medicine*, 57, 1017-1029.
- Cohen-Mansfield J (2008) Understanding the language of behaviour. In Downs M, Bowers B (eds) *Excellence in dementia care: Research into practice*, Open University Press: Maidenhead.
- Colvez A, et al. (2002) "Health status and work burden of Alzheimer patients' informal caregivers: comparisons of five different care programs in the European Union." *Health Policy*, 60(3), 219-233.
- Commissaris CJAM, Jolles J, Verhey FRJ, Kok GJ (1995) Problems of caregiving spouses of patients with dementia. *Patient Education and Counselling*, 25, 143-149.

Compton SA, Flanagan P, Gregg W (1997) Elder abuse in people with dementia in Northern Ireland: prevalence and predictors in cases referred to a psychiatry of old age service. *Int J Ger Psych*, 12(6), 632-635.

Cuijpers P (2005) Depressive disorders in caregivers of dementia patients: a systematic review. *Ageing and Mental Health*, 9, 325-330.

Department of Health (2009) *Living well with dementia: a National Dementia Strategy*.

De Vugt ME, Stevens F, Aalten P, Lousberg R, Jaspers N, Winkens I et al (2003) Behavioural disturbance in dementia patients and quality of marital relationship. *Int J Ger Psych*, 18, 149-154.

Ferri CP, Prince M, Brayne, C, et al (2005) Global prevalence of dementia: A Delphi consensus study. *Lancet*, 366, 2112-2117.

Fossey J, Ballard C, Juszcak E, James I, Alder N, Jacoby R, Howard R (2006) Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: cluster randomised trial. *BMJ*, 332, 756-761.

Georges J, Jansen S, Jackson J, Meyrieux A, Sadowska A, Selmes M (2008) Alzheimer's disease in real life – the dementia carer's survey. *International Journal of Geriatric Psychiatry*, 23, 546-551.

Graff MJL, Vernooij-Dassen M, Thijssen M, Dekker J, Hoefnagels WHL, Olde Rikkert MGM (2006) Community-based occupational therapy for patients with dementia and their caregivers: randomised controlled trial. *British Medical Journal*, 333, 1196.

Graff MJL, Adang EMM, Vernooij-Dassen MJM, Dekker J, Jonsson L, Thijssen M, Hoefnagels WHL, Odde Rikkert MGM (2008) Community occupational therapy for older patients with dementia and their caregivers: cost effectiveness study. *BMJ*, 336, 134-138.

Hosaka T, Sugiyama Y (2003) Structure intervention in family caregivers of the demented elderly and changes in their immune function. *Psychiatry Clinical Neurosci* 57(2), 147-151.

Keady J, Nolan M (1995) A stitch in time: facilitating proactive interventions with dementia caregivers: the role of community practitioners. *Journal of Psychiatric and Mental Health Nursing*, 2, 33-40.

Kitwood T (1997) *Dementia reconsidered: The person comes first*. Open University Press: Buckingham.

Knapp M, Prince M (2007) *Dementia UK*. London: Alzheimer's Society.

Lawton MP (1994) Quality of life in Alzheimer's disease. *Alzheimer Disease and Associated Disorders*, 8(3), 138-150.

Mittelman MS, Roth DL, Coon DW, Haley WE (2004) Sustained benefit of supportive intervention for depressive symptoms in caregivers of patients with Alzheimer's disease. *American Journal of Psychiatry*, 161, 850-856.

Mittelman MS, Ferris SH, Shulman E, Steinberg G, Levin B (1996) Family intervention to delay nursing home placement of patients with Alzheimer's disease: A randomised controlled trial. *Journal of the American Medical Association*, 276, 1725-1731.

Moniz-Cook E, De Vugt M, Verhey F, James I (2009) Functional analysis-based interventions for challenging behaviour in dementia. *Cochrane Database Syst Rev*, 1, 1-7.

Moniz-Cook E, Elston C, Gardiner E, Agar S, Silver M, Win T, Wang M (2008) Can training community mental health nurses to support family carers reduce behavioural problems in dementia? An exploratory pragmatic randomised controlled trial. *Int J Geriatr Psychiatry*, 23, 185-191.

Morgan DG, Semchuk KM, Stewart NJ, D'Arcy C (2002) Rural families caring for a relative with dementia: barriers to use of formal services. *Social Science & Medicine*, 55, 1129-1142.

NICE/SCIE (2006) *Dementia: Supporting people with dementia and their carers in health and social care*. London: National Institute for Health and Clinical Excellence.

Nolan MR, Grant G, Keady J (1996) *Understanding family care: A multidimensional model of caring and coping*. Open University Press: Buckingham.

Norberg A (1996) Perspectives of an institution-based research nurse. *International Psychogeriatrics*, 8, 459-464.

OECD (2002) *Policy issues in dementia care in OECD countries*. OECD: Paris.

OECD (2004) *Dementia care in 9 OECD countries: a comparative analysis*. <http://www.oecd.org/dataoecd/10/52/33661491.pdf> (Accessed on 27 April 2009).

Ory MG, Hoffman RR, Yee JL, Tennsted S, Schulz R (1999) Prevalence and impact of caregiving: A detailed comparison between dementia and non dementia caregivers. *Gerontologist*, 39, 177-185.

Pearlin LI, Mullan JT, Semple SJ, Skaff MM (1990) Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist*, 30, 583-594.

Phinney A, Chesla CA (2003) The lived body in dementia. *Journal of Aging Studies*, 17, 283-299.

Phinney A (2008) Toward understanding subjective experiences of dementia. In Downs M, Bowers B (eds) *Excellence in dementia care: Research into practice*. Open University Press: Maidenhead.

Proctor R, Martin C, Hewison J (2002) When a little knowledge is a dangerous thing: a study of carers' knowledge about dementia, preferred coping style and psychological distress. *Int J Geriatr Psychiatry*, 17, 1133-1139.

Ragneskog H, Asplund K, Kihlgren M, Norberg A (2001) Individualized music played for agitated patients with dementia: analysis of video-recorded sessions. *Int J Nurs Pract*, 7(3), 146-55.

Sabat S (2001) *The experience of Alzheimer's disease: Life through a tangled veil*. Blackwell: Oxford.

Schols JMGA, van der Schriek-van Meel C (2006) Day care for demented elderly in a dairy farm setting: Positive first impressions. *J Am Med Dir Assoc*, 7, 456-459.

Skovdahl K, Kihlgren AL, Kihlgren M (2003) Different attitudes when handling aggressive behaviour in dementia-narratives from two caregiver groups. *Aging and Mental Health*, 7, 277-286.

Sørensen L, Waldorff F, Waldemar G (2008) Coping with Alzheimer's disease. *Dementia*, 7, 287-299.

Spruytte N, Van Audenhove C, Lammertyn F, Storms G (2002) The quality of the caregiving relationship in informal care for older adults with dementia and chronic psychiatric patients. *Psychol Psychother*, 75, 295-311.

Stokes G (2000) *Challenging behaviour in dementia: A person-centred approach*. Speechmark: Bicester.

Teri L, McCurry SM, Logsdon R, Gibbons LE (2005) Training community consultants to help family members improve dementia care: a randomized controlled trial. *Gerontologist*, 45(6), 802-811.

Teri L, Logsdon RG (1991) Identifying pleasant activities for Alzheimer's disease patients: the pleasant events schedule-AD. *Gerontologist*, 31, 124-127.

Teri L, Gibbons LE, McMurry SM, Logsdon RG, Buchner DM, Barlow W E et al (2003) Exercise plus behavioural management in patients with Alzheimer's disease: A randomized controlled trial. *Journal of the American Medical Association*, 290, 2015-2022.

Treolar A, Cooper B, Sweeney J, Kelly N (2001) Night respite care: Relieving the burden on people caring for relatives with dementia. *Nursing Older People*, 13, 14-15.

Twigg J, Atkin K (1994) *Carers perceived: policy and practice in informal care*. Buckingham: Open University Press.

Wimo A, Nelvig J, Adolfsson R, Mattson B, Sandman PO (1993) Can changes in ward routines affect the severity of dementia? A controlled prospective study. *International Psychogeriatrics*, 5, 169-180.

Woods RT (2001) Discovering the person with Alzheimer's disease: cognitive, emotional and behavioural aspects. *Ageing and Mental Health*, 5(1), 7-16.

Zarit SH, Orr NK, Zarit JM (1985) *The hidden victims of Alzheimer's disease: Families under stress*. New York: New York University Press.

Zarit SH, Stephens MAP, Townsend A, Greene R (1998) Stress reduction for family caregivers: Effects of adult day care use. *Journal of Gerontology: Social Sciences*, 53B, S267-S277.

Zarit SH, Zarit JM (2007) *Mental disorders in older adults*, 2<sup>nd</sup> ed. New York: Guilford.