

Quality Dementia Care

Position Paper 2

February 2003

Alzheimer's Australia



Introduction

The purpose of this paper is to promote an understanding of quality dementia care in both residential facilities and the community. It is based on the experience of professional staff within Alzheimer's Australia and is referenced to acknowledge literature in this field.

We expect those working with people with dementia, whether in residential facilities or in the community, will find relevance in the issues outlined in this paper and be able to translate them in practical terms to their particular situation.

There is no single or standard approach to dementia care – no "one size fits all" set of practices. The quality of dementia care is, however, likely to be high if it is driven by:

- a philosophical approach that emphasises person centred care;
- a partnership approach between the care providers, person with dementia and their family and carer;
- a professionally based care environment characterised by strong leadership; and
- adoption of best care practices that reflect the integration of a clear philosophy, current knowledge and applied skills.

Within this framework the needs of individuals can be addressed. The emphasis must be on flexibility and meeting individual needs because:

- there are many different types and symptoms of dementia that impact variously on individuals, even when those individuals are affected by the same illness;
- the nature of the condition changes as it progresses; and
- each individual, their history, current circumstances and relationships are unique.

This flexibility and focus on individual needs demands continual evaluation of existing techniques and trialing and assessing new approaches.



Funded by the Commonwealth Government



Philosophy

Alzheimer's Australia believes that the provision of quality dementia care should be based on the core principles set out below.

1. Valuing the worth of every person.

- All people should be treated with dignity and respect, regardless of their level of disability or the extent of their dependence.
- Care services/providers should understand and respect the intellectual, social and cultural backgrounds, values and beliefs, likes and dislikes and right to privacy of the individual.
- Care practices should aim to support the highest possible quality of life for the individual.

2. Relating to the person rather than the illness.

- Care providers should recognise that dementia affects each person differently and that their needs are both unique and individual.
- People with dementia should never be defined by their illness and resulting disability, nor should illness be the sole basis of care and interaction.
- Symptoms of the illness should be accepted and accommodated as part of the condition, rather than as characteristics of the person.

3. Maximising autonomy, independence and participation.

- People in care should be enabled to participate, within each individual's abilities, in decisions that affect them and activities that interest them.
- The focus of the care and relationships between carers/staff and the person receiving care should be on the latter's capacities and abilities rather than their deficiencies and losses.
- People receiving care should feel in control rather than controlled.
- Restraint should be a measure of last resort for the immediate protection of the client or others and based on thorough assessment and regular review.

4. Responding to the needs of the whole person.

- Care providers should recognise that people with dementia have the same innate human needs as everyone else.
- Care should be flexible and responsive to the individual and their changing needs during the progression of their illness.
- Care should focus on the whole person, including their physical, social, spiritual and emotional needs.
- Care providers should recognise that behaviour is frequently a subconscious but important means of communication.

5. Providing an environment and experiences that are enriching and meaningful.

- People receiving care should feel secure and comfortable in their surroundings.
- The care environment should be designed and developed to support the person.
- The care environment should enrich the person's life and provide appropriate stimulation.
- Activities and experiences should be positive and meaningful for each individual.

6. Care providers should recognize the importance of working in partnership with family and friends of the person with dementia.

- Family and friends of the person with dementia can contribute valuable skills and provide valuable information about the individual's needs, history, values, beliefs and interests.
- Family and friends should be encouraged to work with care staff to assist in creating a positive caring environment.
- Family and friends can work with staff in making the experience of respite more positive.
- Care providers should recognise and respect the right of carers and families to choose the level of involvement they will have in the care process. This will vary between carers and may change over time.

The Care Environment

Alzheimer's Australia believes that quality dementia care is more likely to result if the care environment reflects the following characteristics.

- 1. A culture and philosophy** that emphasises personalised care and which is reflected at all levels of the organisation. A positive attitude that values each individual with dementia is essential.
- 2. Leadership** from senior care managers that promotes ownership of the philosophy by every member of the service and provides inspiration and motivation to all those involved. Prime examples of the responsibilities and initiatives of people in the leadership roles would be to:
 - provide an appropriate physical environment with the equipment, skills training and knowledge necessary;
 - manage and develop staff strategically and understand that rigid institutional care routines and practices are not appropriate for people with dementia
 - provide the systemic means to assist the organisation to achieve best practice in quality dementia care; and,

- provide a formal framework for staff and management to meet regularly for discussion of issues concerning client care – focussing on problem solving and promoting mutual support and teamwork.
3. **Staff** who are knowledgeable and valued as important resources, provided with adequate support and encouraged to respond to behaviours of concern in a positive, creative and flexible manner.
 4. **An environment** that has a warm and "homely" feel. Such an environment would be based on appropriate physical design – but good design, of itself, is not enough. A vital, "value added" feature is the warmth, psychological security and physical comfort which is best created and enhanced by the relationships between the service providers and the people with dementia. An efficient and effective environment would include family, friends and volunteers, providing a genuine sense of partnership in care among all stakeholders.

Key Elements of Care

Alzheimer's Australia believes that the following are the key elements leading to best practice in quality dementia care.

1. **Assessment.** An accurate and detailed assessment of each person with dementia is vital for the development of a tailored care plan for the individual, not only at the time of assessment and/or admission but as part of the ongoing management of a person's care. Staff should be equipped with the skills to accurately assess the circumstances surrounding behaviours, to identify triggers and attempt to remove or minimise these triggers. Staff should have the skills to enable ongoing assessment of the needs of the person with dementia.
2. **Staff selection, training and education.** The selection of competent staff is critical to good outcomes – competence equates to skills, knowledge and attitude. All staff should have access to ongoing training and education, including knowledge about the progression of dementia, the principles of and strategies for providing effective person centred care and, perhaps most important, understanding why behaviours of concern occur and how to respond to them. Staff should be encouraged to look beyond the technical aspects of care to identify and implement improvements that enhance the quality of life of clients. This should include modelling and promoting positive attitudes towards individuals with dementia and their families and carers among staff.
3. **Individualised care.** A thorough understanding of the individual person is critical to quality dementia care. Staff should have a comprehensive understanding of the cultural background, personal history, social and family networks and preferences for activities of each person in their care. This is particularly important when people living with dementia in the community use residential respite.
4. **Specialised services.** Access to specialised services that understand and respond to the special needs of an individual with dementia. This includes continence, dental, speech pathology, psychogeriatric services etc.

- 5. Activities.** Good dementia care is about creating opportunities for people to respond appropriately and utilise their abilities. One key factor for some people with dementia is that they may have a reduced capacity to initiate activity or interaction with people. This may be due to a number of factors but it results in the high risk of withdrawal and isolation leading to further loss of capacity. This in turn results in increased care needs and costs for intervention. Activities should be similar to those the person would experience in the community and be related to interests that were important to the person before the onset of dementia or perceived by them as important now. The value of everyday activities (such as eating and bathing) and culturally significant activities in providing opportunities for promoting self-esteem, dignity and feelings of self-worth should not be underestimated.
- 6. Relationships.** There is a need for caring and trusting relationships between staff, the person with dementia and their family. Effective relationships can be fostered in community care or residential settings, for example, by assigning staff teams who provide all the care to groups of clients or residents.
- 7. Communication skills.** Communication between staff and people with dementia should focus around sound understanding and skilled application of appropriate verbal and non-verbal communication techniques tailored to the needs and abilities of the individual. Specific approaches and techniques such as validation, reality orientation and/or reminiscence may be helpful for building empathy between the staff member and the person with dementia. Application of knowledge and techniques drawn from a wide range of therapies (such as music therapy or aromatherapy) may hold benefits, provided their applications are driven by a motivation to accurately and sensitively meet assessed individual needs rather than by indiscriminate, general application.
- 8. Physical environment.** Comfort, security and orientation are a means of encouraging calmness in people with dementia and can be fostered by a well-designed and secure physical environment. Smaller scale, home-style environments also give staff the opportunity to work more effectively with smaller groups.
- 9. Involvement of family and friends.** Families and friends should be provided with information about dementia and encouraged to be involved in the care of their family member or friend. They should be assisted in accessing any additional support services that they may require.
- 10. Flexibility in routines and practices.** A flexible approach by all staff is critical to person centred care. Flexibility includes, for example, acknowledging the independence of the person and focusing on what suits the individual (for example, less emphasis on completion of personal care tasks at particular times; more on matching activity to the individual, rather than coerced involvement in pre-determined activities).

Conclusion

There is no one, overall approach to ensuring quality dementia care. The literature and the experience of people working with people with dementia, their families and carers suggest that when the philosophy, care environment and care practices described in this paper co-exist, then the quality of care is likely to be of a high standard, enhancing the quality of life of the person with dementia.

Nevertheless, there is an urgent need for research to be undertaken which will lead to an increase in our understanding of the approaches that can be identified as the most effective and may, therefore, be used as benchmarks for best practice dementia care.

Alzheimer's Australia – February 2003

References

Kitwood T and Loveday B, *Improving Dementia Care*, Hawker Publications, London, 1998.

Morton I, *Person-centred Approaches to Dementia Care*, Speechmark Publishing Limited, 1999.

Parker J and Penhale B, *Forgotten people: Positive Approaches to Dementia Care*, Ashgate, Aldershot, 1998.

Rosewarne R, *Care Needs of People with Dementia and Challenging Behaviour: Literature Review*, Commonwealth Department of Health and Family Service, Canberra, 1996.

Rosewarne R, Opie J R and Ward S M, *Dementia Specific Care in Australia: An Overview and Future Directions in Special Care Units*, Serdi Publisher, 2000.

Acknowledgements

This paper was developed with the assistance of staff in State Alzheimer's Associations.

Funded by the
Commonwealth Government



Printing and distribution of this
paper sponsored by



The opinions expressed in this paper are those of Alzheimer's Australia and not necessarily those of the Commonwealth Government.