

A Practical Guide for Caregivers of People with Dementia

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This project was undertaken as part of a Deans Scholar Project (2004-2005) under the supervision of Dr. Nancy Pachana.

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Contents

Introduction

What is Dementia?	1
Who is a caregiver?.....	1
Caregiver Health.....	1

Section 1 - As a Caregiver, what can you do for yourself?

Section 1.1 - Support Groups.....	
Section 1.2 - Taking a Break: Respite Care.....	
Section 1.3 - Taking a Break: At Home.....	
Section 1.4 - Education.....	
Section 1.5 - Individual Counselling.....	
Section 1.6 - Managing Stress.....	
Section 1.7 - Family Therapy/Getting help from others.....	
Section 1.8 - Grief.....	
(By Sarah Price)	

Section 2 - Practical tips for caring for someone with dementia.

Section 2.1 - Managing Behavioural and Psychological Symptoms of Dementia.....	
Section 2.2 - Techniques for Observing and Managing Behaviour.....	
Section 2.3 - General Overview and Tips.....	
Section 2.4 - Driving.....	
Section 2.5 - Communication.....	
Section 2.6 - Telephone Tips.....	
Section 2.7 - Physical Attachment to Caregiver.....	
Section 2.8 - Sleep Disturbances.....	
Section 2.9 - Delusions and Hallucinations.....	
Section 2.10 - Paying Bills and Managing Finances.....	
Section 2.11 - Wandering.....	
Section 2.12 - Hiding and Rummaging.....	
Section 2.13 - Aggression and Sun-downing.....	
Section 2.14 - Sexual Inappropriateness.....	
Section 2.15 - Dressing.....	
Section 2.16 - Toileting.....	
Section 2.17 - Bathing.....	

Section 2.18 - Lighting.....
Section 2.19 - Suspicion.....
Section 2.20 - Eating.....
Section 2.21 - Safety.....
Section 2.22 - Tips for Distracting.....
(By Louisa Young)

References.....

Useful Resources.....

Introduction

What is dementia?

Dementia is an irreversible, progressive brain disease which causes a gradual decline in a person's memory, thinking and ability to learn. Personality changes may also occur which impede upon the person's social and working life. The changes in brain functioning experienced by people with dementia affect their physical, social and emotional life as well as the lives of those around them (Australian Government, 2002).

There are a number of types of dementia, but the most common is Alzheimers Disease. Alzheimers Disease, like any kind of dementia is not a normal part of aging but can happen to anyone at anytime. Currently it is estimated that 162 000 people in Australia who are over the age of 65 have dementia. This risk increases steadily as people age from 65 (1 in 2000) to 85 (1 in 4) (Australian Government, 2002).

Who is a caregiver?

Caregivers "provide tangible, financial, emotional or informational and coordinated support to an impaired family member" (Coon, Gallagher-Thompson & Thompson, 2003).

People who provide care to a family member in their own home are generally known as informal caregivers. Informal caregivers can be defined as people who provide care without monetary compensation (Patterson & Grant, 2003; Vitaliano, Zhang & Scanlan, 2003).

Caregiver health

Informal caregivers are very important people and are invaluable to the health care system and the people they care for. The care they provide is critical and without it the person with dementia would not be able to sustain themselves. For this reason, caregivers need to look after every aspect - mental, physical and emotional - of their own health. Unfortunately, people who care for a family member with dementia have high stress levels and

suffer from a range of health problems (Vitaliano, Zhang & Scanlan, 2003).

It has been reported that 66% of caregivers suffer from emotional, mental and physical illnesses as a result of the stress of caring for a person with dementia (Davidson, 1996) and that 75% of caregivers of people with dementia are depressed at one time or another (Bowlby Sifton, 2004).

In Section 1

The following pages discuss certain activities which caregivers of people with dementia may find helpful. As each caregiver, the person being cared for and their environment varies, different activities will work for different people.

Each part of section one includes a description of the activity and why it is useful. Organisations which offer these services are mentioned along with a contact number at the end of each part.

In Section 2

There are a number of symptoms and behaviours which people with dementia display which caregivers find difficult to deal with. These include things like wandering, aggression, anxiousness, hallucinations and delusions. These will be discussed in Section two along with a number of tips to manage these behaviours.

Section 1 - As a Caregiver, what can you do to help
yourself?

1.1 - Support Groups

Support groups offer emotional as well as practical support to caregivers. Many caregivers find support groups very beneficial for a number of reasons. These include the following:

- Support groups allow caregivers to share their own experiences with others who understand what you are going through (Bowlby Sifton, 2004).
- Support groups provide carers with a sense of belonging and lets them know they are not alone. They allow caregivers to share their stories and not feel like they are being criticized (Coon, Gallagher-Thompson & Thompson, 2003; Davidson, 1996).
- Support groups allow social contacts to be made and maintained (Coon, Gallagher-Thompson & Thompson, 2003). Many people who make contacts with people in a support group also see these people at outside the formal support group and find that they are a constant source of company (Gordon Park Dementia Support Group, 2005).
- People who are new to caregiving also find the knowledge and advice of people who have been caregiving for a number of years is invaluable (Gordon Park Dementia Support Group, 2005).
- Many support groups also hold educational sessions where a guest speaker comes to talk about a particular issue or a useful video may be shown (The Alzheimers Association website - www.alzheimers.org).
- Support groups also allow you to have a break and recharge your batteries even if it is only for a few hours (Alzheimers Association Queensland website - <http://www.alzheimersonline.org>).
- Support groups are a place where information can be given and received.
 - This information may be about a number of things:-
 - * services and programs in your local area
 - * how to look after yourself and learn to relax
 - * how to manage problem behaviours in the person you are caring for.
 - * in addition, other carers may be able to recommend a good

doctor, social worker, psychologist etc.
(Australian Government, 2002; Davidson, 1996)

Support groups are usually held once a month and there are no joining fees or costs (excluding a small amount for tea/coffee and biscuits). You do not need to sign anything and are not committed to attending everytime a meeting is scheduled.

Support groups are offered by a large number of organisations such as hospitals, churches, community groups, local councils etc. Telephone support groups are also offered by a number of organisations for people who are unable to make it to the meeting place.

To find out about support groups in your area, please call the Community Carers Resource Centre on 1800 242 636. They can also send you a booklet which includes a list of the support groups in Brisbane.

1.2 - Taking a Break: Respite Care

Why is it important to take a break?

Taking care of a person with dementia is physically and emotionally tiring and stressful. It is important that the caregiver looks after themselves as their well being has a large impact on the quality of life of the person being cared for. No one will benefit if the caregiver is resentful and reluctant and there may be no one to care for the person with dementia if the caregiver is too ill to carry on (Alzheimers Australia website, <http://www.alzheimers.org.au>; Bollard, O'Brien, James & Swann, 2001; Bowlby Sifton, 2004; Davidson, 1996).

When the caregiver takes a break it also gives the patient an opportunity to socialise, meet people and get used to other people caring for them (Alzheimers Australia website, <http://www.alzheimers.org.au>).

What is respite care?

Respite care involves the person with dementia being cared by a someone other than the primary caregiver, so that the caregiver can take a break. There are a large number of options when you are considering respite care.

- Day Centre Respite - the person with dementia spends the day a couple of times a week at a respite centre with other dementia patients.
- Evening, overnight and weekend respite - the person with dementia spends the evening, night or weekend at a respite centre.
 - In home respite/home visiting services - an individual comes to the home to interact with the person with dementia for a few hours while the primary caregiver takes a break. It may also involve a respite officer or family member taking the patient to an event outside the home, such as to church, to their support group, to a football game etc. (Alzheimers Association Queensland website – <http://www.alzheimersonline.org>).
- Short-term residential respite - the person with dementia is cared for in one week blocks.

- Emergency Respite - occurs when an emergency takes place which the caregiver needs to attend to and so cannot care for the person with dementia.
- Flexible Residential Respite - involves organising holidays for both the caregiver and the person with dementia or the whole family. This allows them to get away from their daily routine and have a break together.

Respite care is offered by many organisations such as church groups, local councils and community groups.

To find out where your local respite centre is call the Carer Respite Centre on 1800 059 059.

1.3 - Taking a Break: At Home

There are many ways to take a break in your own home which do not involve a lot of time, money or energy. Try to do something that brings you pleasure everyday, even if it is only for a short time, as it will make you happier (Bowlby Sifton, 2004).

Ways to take a mini break at home:

- Have a spoil me box which contains things that you like and take a thing from the box when you feel you need to be cheered up.
- Close your eyes and imagine a special past experience.
- Practice relaxation techniques.
- Listen to your favourite song.
- Reread a favourite letter or card.
- Reread a passage or poem from a book.
- Have a hot drink.
- Call a friend.
- Enjoy a plant or favourite flower.
- Light a candle and watch the flame.
- Read the comics in the paper or a joke/humorous book.
- Look at a photo album.
- Soak your feet in warm water with Epsom salts.
- Do some quick stretching.
- Make something for dinner that you really enjoy.
- Do a few minutes of brisk physical activity.
- Take up a craft or learn to sew.
- Put on an outfit that makes you feel great.
- Gently massage your hands and feet.
- Heat a moist hand towel and place it over your eyes and forehead (Bowlby Sifton, 2004).
- Play the computer (Farran & Loukissa, 2004).
- Pat a dog or cat.

Pets have a therapeutic effect on those who care for people with dementia. Pets, especially adult animals can act as a distracter and a source of company (Gray-Davidson, 1996). They have been found to be particularly effective for younger (40-45) woman caregivers

(Fritz, Farver, Hart & Kass, 1996).

1.4 - Individual Counselling

A caregiver may feel they need individual counselling for a number of reasons. They may simply want to talk to someone about their problems, gain emotional support, learn how to manage their stress, learn new coping skills, learn practical problem solving techniques, they may wish to gain knowledge, work through role transition issues or grief and loss issues (Australian Government, 2002).

While some people make use of individual counselling for minor problems, severe cases of psychopathology may result in a referral from the GP to attend individual counselling. These situations include complex cases of depression, suicidal ideation or substance abuse (Coon, Gallagher-Thompson, Thompson, 2003). Gallagher, Thompson and Steffen (1994) found that after individual counselling 71% of caregivers were no longer depressed and both CBT and psychodynamic therapy were equally effective. Similarly, Schmidt, Bonjean, Widem and Schefft (1988) found that individual counselling which included problem solving and emotional expression reduced psychiatric symptoms in caregivers and improved the relationship between the caregiver and patient.

A study by Saad et al. (1995, cited in Ballard et al., 2001) found that caregivers with more active rather than passive coping strategies and an internal locus of control were less likely to become depressed. It is for this reason that cognitive-behaviour therapy (CBT) may be useful for caregivers of people with dementia. CBT interventions focus on an array of issues. For example they help with the management of distress, developing new ways of thinking about problems and new coping skills to manage problem behaviours, as well as advice about using local community services (Ballard, O'Brien, James & Swann, 2001).

If you find you are in need of some immediate counselling the Dementia Helpline (Ph: 1800 639 331) is a free call and staff are available 24 hours a day, 7 days a week.

There is also a National Carer Counselling Program which offers counselling either over the phone or face to face. This service is available in Brisbane,

Toowoomba, Rockhampton, Townsville and Cairns. You can contact them through the Commonwealth Carer Resource Centre on 1800 242 636, Monday to Friday between 9am and 5pm.

In addition, Centrelink employs social workers who can provide individual counselling, as well as information and referrals, if they are needed. To make an appointment, phone 13 1021.

1.5 - Family Support, Meetings and Therapy

Family Support

As the primary caregiver, you are under a large amount of pressure and therefore it is important that you try to gain support from your family. There are a number of ways that your family can help you but there are a few things that you need to do to ensure their assistance.

- Tell your friends and family as soon as possible after you find out and hold a family meeting to discuss each member's responsibilities.
- Talk with your family openly at all stages.
- It may also be beneficial to take other family members with you to the doctor as well as borrow books and videos for them, so they can increase their knowledge (Australian Government, 2002).
- Ask for practical help. Do not hint at what you want but ask for specific commitments from the person. Also, be accepting of help from others, they may only ask once (Davidson, 1996).

Family Therapy

Family therapy is a psychosocial approach which treats emotional and behavioural problems within the family. Its primary aim is to reduce the stress which one or more members may be feeling (Coon, Gallagher-Thompson, Thompson, 2003).

Marriott, Donaldson, James and Burns (2000) discovered that after cognitive behavioural family therapy, which included carer education, stress management and coping skills training, Alzheimer's caregivers experienced symptom alleviation.

1.6 - Managing Stress

A situation is considered stressful when an individual feels the demands on them are greater than the resources they have to cope with them (Coon, Gallagher-Thompson, Thompson, 2003). People experience varying levels of stress in their caregiving role depending on their age, gender and relationship with the person they are caring for (Le Navenec & Vanhof, 1996).

A caregiver's level of stress is associated with a greater number of visits to the doctor and a greater number of prescriptions (Bollard, O'Brien, James & Swann, 2001). For your own well being, it is therefore important to learn to cope with or manage your stress.

Here are a few tips on how to deal with stress:

- Have a consistent schedule
- Take each day as it comes. Make a list of what you have to do and follow it.
- Take stress management classes.
- Use relaxation or take deep breaths in times of stress.
- Talk things over with others or a professional such as a counsellor, therapist, psychologist, minister, priest or call a helpline.
- Admit you are not a perfect caregiver
- Be accepting of help from others (Davidson, 1996).
- Be realistic about what you can expect of yourself (Alzheimers Australia website, <http://www.alzheimers.org.au>)
- Think about whether there is a faster or better way to do a task
- Can somebody else do something for you? If so, ask them.
- Find the joy in day to day pleasures.
- Have a positive attitude towards yourself and the tasks you do.
 - Research has shown that people who identify more positive aspects of the caregiving role feel less burdened and less depressed than those who don't (Patterson & Grant, 2003).
- Try to balance your work, rest and play.
- Learn to laugh at yourself and with the person you are caring for.
- Try meditation
- Find a healthy way to express your feelings.
- Be forgiving of your mistakes and learn from them.
- Try to have a healthy lifestyle

- Follow a balanced diet
- Exercise regularly
- Avoid excess caffeine
- Drink water
- Get a good amount of sleep each night (Bowlby Sifton, 2004).

1.7 - Education

Knowledge is a great source of power. Try to learn as much as you can, it will increase your confidence and make you feel capable and competent in

your caregiving (Bowlby Sifton, 2004). Knowledge also fosters realistic expectations and can increase self efficacy and mastery which in turn are related to lower levels of depression (Coon, Gallagher-Thompson, Thompson, 2003).

There is information available on any question you may have regarding dementia, caregiving skills and how to look after yourself and there are a number of ways to gain this information. You can read articles and books, watch videos, go to presentations/talks and search the internet.

Many organisations have books and videos you can borrow and many hold information sessions.

The Carer's Resource Centre has a library with over 1500 books on caring and lends them out. They will also mail them to you free of charge if you are unable make it to the centre. The centre can also mail you a book called, "The Carer Experience: An essential guide for carers of people with dementia", which contains a section on useful books, videos and website addresses as well as information on caring for someone with dementia.

The Alzheimer's Association of Queensland has an education helpline which is a free call (1800 180 023).

The Dementia Helpline (Ph: 1800 639 331) can put you in contact with resource centres which have libraries, videos, journals etc.

The Department of Veterans Affairs (Ph: 13 32 54) can also answer many of your questions as well as provide you with information.

1.8 - Grief

Grieving as a process

For caregivers of people with dementia, grieving is a process and not simply something that occurs once the person with dementia has passed away. As caregivers take on the caregiving role, they may have to face the loss of their career, their friends and their freedom (Australian Government, 2002). They may also grieve for the loss of long term plans, dreams and shared goals, such as a traveling around the world or watching their grandchildren grow up (Betts-Adams & Sanders, 2004).

Furthermore, they are aware of the losses the person they care for is experiencing, such as a loss of their ability to remember or communicate. One caregiver of a person with dementia said “you are watching them die little by little (Gordon Park Dementia Support Group, 2005)”. In parallel with these losses in the person with dementia are the losses the caregiver suffers as a result. For example, a loss of memory means the caregiver can no longer play card or other games the couple may have played together. In addition, as a loss in communication occurs, conversations that were once enjoyed by both partners can no longer take place (Bowlby Sifton, 2004).

Grieving once the person with dementia has passed away

Different people react to grief differently. You may experience shock, disbelief and denial, anger and resistance, despair or any combination of these (Australian Government, 2002).

The following suggestions may help you to work through your grief:

- Accept assistance from your family, friends, religious ministers and others. They can help you to express your feelings and you can help each other to adjust to your loss.
- Talk about your thoughts and feelings regarding the person before and after they became ill. Your memories, both good and bad, can help you accept the situation (Australian Government, 2002).
- Talking with an experienced counselor is also an excellent way to deal with grief (Bowlby Sifton, 2004).

Section 2 - Practical tips for caring for someone with
dementia.

2.1 - Managing Behavioural and Psychological Symptoms (BPSD) of Dementia

The following are some suggestions for managing BPSD in home-care situations. It is important to note that the effectiveness of a strategy will vary between individuals (Gordon Park Dementia Support Group, 2005) meaning that the caregiver may need to try various approaches before finding something that works. Individuals have varying cognitive abilities and the effects of cognitive impairment will vary between persons (Weiner, 1996). Therefore, the caregiver needs to use discretion in determining which strategy is likely to best suit the person's abilities. Further, as the illness progresses, strategies will have to be modified to make them appropriate for the person's current ability level.

It is important to understand the person's personality -- to know what they like and what they do not -- as personality traits become marked with age (Weiner, 1996). An understanding of the person with dementia's personality and disposition will help identify potential BPSD and manage existing BPSD. For example, if the person has always enjoyed social contact, they are likely to still enjoy it.

Many of the suggestions to manage BPSD are based around the caregiver's own observations of the causes of the behaviour. It is important to observe the person with dementia to understand the reasons behind the behaviour so that a suitable management strategy can be developed (Holroyd 2004).

Some techniques for observing behavioural responses will be addressed first. This will be followed by a series of common daily activities which may cause BPSD's with suggestions on how to make these easier for the person with dementia and the caregiver. Finally, some miscellaneous issues such as activities to occupy the person and distract them from problematic behavioural symptoms will be addressed.

2.2 - Techniques for Observing and Managing Behaviour

Technique 1.

When starting the observation, consider whether the behaviour is due to:

1. Environmental factors
2. Other medical causes
3. Psychiatric causes
4. The result of dementia itself (Holroyd, 2004).

Technique 2.

ABC:

A = Antecedence (did anything trigger the behaviour)

B = Behaviour of concern

C = Consequences of the behaviour (Weiner 1996; Teri, 1998)

Technique 3.

- Three R's: repeat, reassure and redirect approach. Repeat the explanation and redirect the person to avoid problematic behaviour.

Technique 4.

- know the person's preferences
- change the context of the behaviour
- offer rewards to the person that accord with their preferences when it is successful (Ballard et al., 2001).
 - * NB: if it is not possible to alter the environment, provide extra positive reinforcement and reassurance (Ballard et al., 2001)

2.3 - General Overview and Tips

- Know the person's personality and history as this allows you to make better informed behavioural management decisions (Weiner, 1996; Sloane & Gleason, 1999).
- Cooperate with your GP to form a team approach with other professionals. A multi-disciplinary team is effective in reducing BPSD, particularly if the intervention is commenced early in the course of the disease (Cummings et al., 2002; Opie et al., 1999).
- Make sure all medical conditions are addressed and others are ruled out (Cummings et al., 2002). For example, persons with dementia often experience depression as well (Weiner, 1996; Sloane & Gleason, 1999).
- The person with dementia may need pharmacological interventions (Sloane & Gleason, 1999) but combine these with non-pharmacological interventions (Cummings et al., 2002).
- Check what side effects may occur as a result of any new medications (Gray-Davidson, 1996).
- If major changes occur after commencing medications, they should be changed, reduced or stopped completely (Gray-Davidson, 1996).
- Avoid anxiety-producing situations (Weiner, 1996).
- Over the course of the illness, the person's ability to cope with stress decreases, meaning that the environment must become increasingly more simple and supportive (Jones, 1995).
- Dementia is irreversible, allow the person to do things for themselves but be careful not to challenge them too much. The caregiver will need to support and fill in to a greater extent for the person as their abilities decrease (Weiner, 1996).

- Acknowledge the person's disability (Weiner, 1996).
- Help them develop coping strategies (praise the person for what they can do) or use distractions (Weiner, 1996; Cummings et al., 2002; Wiscott, Kopera-Frye & Seifert, 2001).
- Instead of teaching the person what they cannot do (therapeutic model), the caregiver and environment should make up for deficits by filling in for person's missing functions or to eliminate the need for them (prosthetic model) (Sloane & Gleason, 1999).
- Psychotherapy may be useful in some cases (Jones, 1995).
- Create a set routine as early as possible (Weiner, 1996; Cummings et al., 2002; Bowlby Sifton, 2004).
- Appreciate non-verbals used to show appreciation (Bowlby Sifton, 2004).
- Treat the person with dignity as they are an adult who wants to make decisions (Bowlby Sifton, 2004).
- Do activities slowly to reduce agitation (Ballard et al., 2001).
- Keep the environment familiar and simple (Weiner, 1996; Gitlin, Corcoran, Winter, Boyce, & Huack, 2001; Bowlby Sifton, 2004).
- Distract or remove environmental stimuli if there is confusion (Weiner, 1996).
- Balance sensory input -- do not over-stimulate or under-stimulate (Weiner, 1996; Sloane & Gleason, 1999).
- Avoid excess alcohol consumption (Wiscott et al., 2001).
- Try ignoring certain behaviours (for example shouting may be simply to get the caregiver's attention and giving such attention when the person shouts would reinforce this behaviour) (Ballard et al., 2001; Opie et al.,

1999).

- Reality orientation is useful as it reminds the person with dementia of facts about themselves, their past and their environment (Ballard et al, 2001).
- Empathise with the person and their confused behaviour - validation therapy helps older people to communicate (Ballard et al., 2001; Opie et al., 1999).
- Avoid confrontation (Weiner, 1996; Australian Government, 2002).
- Make sure the person has something to do (Bowlby Sifton, 2004).
- Find activities that the person will view as productive (preparing simple meals to repetitive tasks or working with someone in partnership) (Weiner, 1996).
- Continue to allow the person to engage in activities and responsibilities where possible (Australian Government, 2002).
- Try to keep them involved in things they like as involving the person helps maintain dignity and avoids embarrassment over their disability (Australian Government, 2002).
- Respond to the person's emotional needs (Bowlby Sifton, 2004).
- Live in the moment, enter the person's world to understand their needs (Bowlby Sifton, 2004).
- Keep a diary daily with events and visitors. When the person is feeling lonely, read the diary to them so they can see that people love them (Australian Government, 2002).
- Use humour about their memory loss (for example, society's extensive record keeping is proof of memory loss not being uncommon) (Weiner, 1996).

- Get the person's attention by using the senses and movement (Bowlby Sifton, 2004).
- Keep the focus on a single sense to encourage a response (Bowlby Sifton, 2004).
- Involve people with dementia in active teaching about dementia and also as research subjects (Weiner, 1996).
- Don't challenge defence mechanisms (let the person blame you for stealing etc.) (Weiner, 1996).
- The caregiver needs to take a leadership role in activities (Weiner, 1996).
- The person will relax if they feel they have someone to depend on (Weiner, 1996).
- If an activity involves learning new principles, it is likely to be frustrating for the person with dementia (Weiner, 1996).
- Keep pictures and furniture of the former home to create a feeling of familiarity (Weiner, 1996).
- Orientation to the month, day and week may be useful in milder cases of dementia (Weiner, 1996).
- Don't threaten abandonment - this will lead to anxiety (Weiner, 1996).
- Acknowledge the person's feelings and then do something about their needs (Gray-Davidson, 1996).
- Provide reassurance if the person continually brings up past trauma. Bringing it up shows fear, so empathise and recognise the feelings and the wrong before providing reassurance that you will take care of the issue (Gray-Davidson, 1996).

- Recognise the creation of fantasy as a coping device (Gray-Davidson, 1996).
- Use cues in the person's language to understand feelings (examples, wanting relative = loneliness; wanting home = loss) (Gray-Davidson, 1996).
- Use lots of physical contact to show things are ok (Gray-Davidson, 1996).
- "... physical movement should be slow, firm and leisurely" (Gray-Davidson, 1996).
- Seek outside assistance where necessary as family intervention reduces carer stress and improves problem behaviour (Marriott et al., 2000).
- Being able to manage dementia behaviour reduces problem behaviour (Marriott, et al., 2000; Opie et al., 1999).
- If agitation continues to be caused by a particular activity, consider whether the activity or situation is really necessary in the person's life (Opie et al., 1999).

2.4 - Driving

Getting a person with dementia to gradually give up driving, for their own safety as well as the safety of others, is often difficult. Some tips are:

- Say that the doctor is concerned about them driving to take the responsibility away from the caregiver (Weiner, 1996).
- Make excuses that the car is being repaired, someone has borrowed it or that the keys have been misplaced to avoid confrontation (Weiner, 1996).
- Arrange with a friend or relative to take the car for "repairs" (Australian Government, 2002).
- Ask the doctor to suggest to the person that they should stop driving (Australian Government, 2002).
- Use public transport or walk short distances rather than drive (Australian Government, 2002).
- Get in to the car before the person has a chance to drive and explain that it is your turn to drive (Australian Government, 2002).
- Hide or remove the car keys (Australian Government, 2002).
- Arrange a driving test with the Transport Department (Weiner, 1996; Australian Government, 2002).

2.5 - Communication

- Have knowledge of the person's abilities and use this to talk with them using language they understand to avoid frustration (Weiner, 1996; Gray-Davidson, 1996; Opie et al., 1999).
- Socialise the person as much as possible to encourage communication (Weiner, 1996).
- Use the person's name when speaking to them (Weiner, 1996; Australian Government, 2002).
- Use the person's first name over their maiden name as this is more likely to be remembered (Weiner, 1996).
- Talk to the person in the person's presence, not about them (Australian Government, 2002).
- You can use touch as reassurance (Weiner, 1996).
- Speak at the same physical level as the person (Gray-Davidson, 1996).
- Don't over-simplify -- persons are often aware of their own and others feelings (Gray-Davidson, 1996).
- Questions with only one correct answer should be avoided as they set the person up for failure so it is better to rely on opinion questions (Bowlby Sifton, 2004).
- Approach the person from the front so as to avoid surprise (Gray-Davidson, 1996; Australian Government, 2002).
- Ensure that any hearing aids are turned on and that the person can see you (Australian Government, 2002).
- Ensure eye contact and place your hand on their shoulder to get their attention (Gray-Davidson, 1996; Australian Government, 2002).
- Avoid memory questions because this will cause frustration (Gray-

Davidson, 1996).

- Use photos to remind the person of family members (Gray-Davidson, 1996).
- Rely on the present over the past or future (Gray-Davidson, 1996).
- Use repetition (Weiner, 1996).
- If the person can read, the use of cards may avoid repetition (Opie et al., 1999).
- Pay attention to the message behind the question. The meaning is usually the same -- the need for security and love. Answer the need beneath the question (Gray-Davidson, 1996; Australian Government, 2002).
- Avoid literal answers as these will have to be repeated many times (Gray-Davidson, 1996).
- Asking what time it is may be a sign of boredom. Therefore, help fill in time - allow the person to come and help with tasks (Gray-Davidson, 1996).
- Asking for home may reflect insecurity and a lack of knowing one's place in the world. Acknowledge the person's feeling of loss and then offer them reassurance that you are there to help (Gray-Davidson, 1996).
- Asking for parents may mean that love and security are wanted (Gray-Davidson, 1996).
- Try lots of solutions to find the one that works (Gray-Davidson, 1996).
- Introduce people by name and have the person with dementia repeat the name to avoid embarrassment of not being able to identify people in social situations (Weiner, 1996; Gray-Davidson, 1996).
- Answer repeated questions succinctly and provide distraction (Weiner,

1996).

- Break the activity down -- use step by step instructions (Weiner, 1996; Cummings et al., 2002).
- Use a combination of verbal and non-verbal cues as non-verbal cues (such as facial expression and hand gestures) are maintained longer than verbal communication (Weiner, 1996; Australian Government, 2002).
- If you are engaging in a new activity, keep calling the person's name and placing your hand on their arm and entering their field of vision to get their attention (Weiner, 1996).
- It is better to be overly repetitive than cause frustration or aggravation (Weiner, 1996).
- Identify yourself before addressing the person by name (Weiner, 1996; Gray-Davidson, 1996; Australian Government, 2002).
- Use simple words and sentences (Weiner, 1996; Australian Government 2002; Gitlin et al., 2001; Small, Gutman, Makela & Hillhouse, 2003).
- Break tasks into smaller parts (Gitlin et al., 2001).
- Remove distractions (Small et al., 2003).
- Smile and use humour (Australian Government, 2002).
- Use statements over questions (Australian Government, 2002).
- Wait for a response from the person before continuing (Australian Government, 2002).
- Explain what is happening and what you are going to do (Australian Government, 2002).
- Repeat or rephrase your communication if you do not receive a response

(Australian Government, 2002).

- Allow for the time a damaged brain takes to understand and process information (Australian Government, 2002).
- Remember that your tone of voice is important (Australian Government, 2002).
- Use touch with care and stop if it causes agitation (Australian Government, 2002).
- Ask one question at a time (Weiner, 1996).
- Be specific, use nouns (chair, table) instead of it or there (Weiner, 1996).
- Speak slowly and enunciate your words (Weiner, 1996).
- For those with sensory disabilities, use touch with the vision impaired dementia person and gestures with the deaf (Weiner, 1996).
- Speaking louder may help the deaf person but remember to keep the tone of the voice lower. Speaking louder does not do anything for those with cognitive impairment only (Weiner, 1996).
- Make positive statements unless it is a safety issue (Let's go this way rather than don't go that way). This gives the person a feeling of guidance rather than criticism (Weiner, 1996).
- Respond to the sense being used - i.e. if the person says something feels good then use kinesthetic words to explore the situation (Weiner, 1996).
- Avoid using "why" questions as it is unlikely that the person will be able to respond to these (Weiner, 1996).
- A better approach is to offer an explanation that gives the person an option to respond with yes or no -- i.e. no open-ended questions (Weiner, 1996; Australian Government, 2002; Small et al., 2003).

- Drawing, painting, etc may be used as a non-verbal way (along with music and dancing) for the person to show what they want (Ballard et al., 2001).

2.6 - Telephone Tips

- Put the answering machine on so that the person is not placed in the position of having to remember messages (Weiner, 1996; Gray-Davidson,

1996).

- Have two phones in the house so that you can assist the person in phone conversations and they can feel part of the conversation (Gordon Park Support Group, 2005).
- If the person gets annoyed with the phone, turn the ring down, put the answering machine on or go into another room with the phone (Gray-Davidson, 1996).

2.7 - Physical attachment to caregiver

- Use a soft blanket, dolls or soft toys as a substitute (Weiner, 1996).

- Use respite services for a break (Cummings et al., 2002).
- Consult friends or relatives to see if they can stay with the person for a couple of hours.
- Encourage the person with dementia to tell stories of themselves as this helps with socialisation (Weiner, 1996).
- Step up physical contact: stroke arms, kiss etc. in ways that are acceptable to the person (Gray-Davidson, 1996).
- Just explain where you are going and that you will be back (Gray-Davidson, 1996).
- Distract the person by finding an activity that they enjoy.

2.8 - Sleep Disturbances

- Check that this is not being caused by medications (Weiner, 1996).

- Discuss sleeping medications with the person's GP (Australian Government, 2002).
- Check to make sure there are no underlying medical conditions that could be causing the disturbance.
- Avoid stimulants such as tea and coffee (Weiner, 1996; Australian Government, 2002).
- Minimise stimulation to encourage sleep (Weiner, 1996).
- Moderate amounts of stimulation lead to awakening (Weiner, 1996).
- The more severe the dementia, simpler and fewer stimuli should be used (Weiner, 1996).
- The person with dementia may be able to tolerate more stimulation in the morning than in the afternoon (Weiner, 1996).
- They may be more confused in the evening (sun-downing) as the person becomes more fatigued (Weiner, 1996).
- Select the same time to rest as the person with dementia (Weiner, 1996).
- Use a reclining chair to rest during the day as this may stop confusion about the difference between night and day (Weiner, 1996).
- A back massage may be good for helping them to rest (Weiner, 1996; Australian Government, 2002).
- A mattress on the floor allows unrestrained sleep (Weiner, 1996).
- As long as there is no danger, let the person wander around the house (Gray-Davidson, 1996).
- Negotiate the person back to bed -- soothing music, food, drink, massage etc. (Gray-Davidson, 1996).

- Remind the person when it is time for sleep (Australian Government, 2002).
- Keep a sleeping routine based on the person's lifestyle (Australian Government, 2002).
- Go for walks in the morning and afternoon as this is relaxing and good exercise (Australian Government, 2002).
- Leave the light on for safe movement around the house (Australian Government, 2002).
- Orient to time by using calendars, clocks and newspapers (Cummings et al., 2002).
- Use different coloured or graphic labels on furniture to help with orientation around the home (Cummings et al., 2002).
- Use lighting to reduce restlessness at night (Cummings et al., 2002).
- Avoid glare, excess noise and clutter (Cummings et al., 2002).
- Try to ensure regular sleep to avoid problems due to exhaustion (Holroyd, 2004).

2.9 - Delusions and Hallucinations

- Orient gently with reality (Weiner, 1996).
- "Communicating, understanding and acceptance" should be used with delusions. Distract person into another activity (Weiner, 1996).

- Vision and hearing should be checked (Australian Government, 2002).
- Check the person's medications (Gray-Davidson, 1996).
- Rooms should be well lit so that there are no shadows that could be mistaken for objects (Australian Government, 2002).
- Reassure the person if they are fearful (Australian Government, 2002).
- Encourage the person to explain to you what they have seen and heard (Australian Government, 2002).
- Discuss any feelings the hallucinations produce (Australian Government, 2002).
- Do not argue with the person (Australian Government, 2002).
- Try to understand what the hallucination could mean to the person (Australian Government, 2002).
- Distract the person (Australian Government, 2002).
- Simplify the environment so that there are not many things happening at once (Australian Government, 2002).

2.10 - Paying Bills and Managing Finances.

- If this task is too difficult, tell the person that you do not want to trouble them with it but allow them to observe you doing the task (Weiner, 1996).
- Allow the person to participate in the activity as much as possible.

2.11 - Wandering

- The person with dementia may respond to written prohibition if it is a mild case (Weiner, 1996).
- They may respond to "no" accompanied by a gesture (Weiner, 1996).
- Make the door opening into a two-step process, undoing a latch and

turning a knob (Weiner, 1996).

- You can change the physical environment to make it more enriching -- this does not need to be an expensive change (Opie et al., 1999).
- Exiting has been reduced when a cloth (colour was irrelevant) was stretched across the door to hide the doorknob (Opie et al., 1999).
- Painting the doorknob the same colour as the door has also reduced exiting (Opie et al., 1999).
- Attaching a "secure cover" to the door knob reduces exiting (Opie et al., 1999).
- Putting a mirror in front of the door may act as a distraction (Opie et al., 1999).
- A study used corridors (in nursing home) to create a rainforest environment (e.g. nature scene murals, rainforest scenes, music etc.) or home scene (e.g. old photos and armchairs) which stimulated persons and reduced agitation (Opie et al 1999).
- Use other activities as distractions (Weiner, 1996).
- Walking a regular route can often reduce wandering and make the person easily traceable (Weiner, 1996).
- Red or yellow tape can form effective boundaries to stop wandering (Weiner, 1996).
- Ensure the person has an ID bracelet (Gray-Davidson, 1996; Australian Government, 2002).
- Sew the person's name and address into their clothing (Gray-Davidson, 1996).
- Ask the local police to put the person's picture on file in case of loss

(Gray-Davidson, 1996; Australian Government, 2002).

- Alert your neighbours and friends to the situation so they can help the person and look out for them (Australian Government, 2002; Gray-Davidson, 1996).
- Visit the person's favourite places regularly (shops, park etc) (Australian Government, 2002).
- Install deadlocks for security (Australian Government, 2002).
- Hide the door keys from the person so that they cannot exit (Australian Government, 2002).
- Put a lock on the gate and check that the garden is safe so that the person with dementia can wander around the garden (Australian Government, 2002).
- Put a bell or alarm on the door to alert you when the person is opening it (Gray-Davidson, 1996).
- Limit access to doors out of house (Gray-Davidson, 1996).
- A radio controlled beeper could be used to keep track of the person (Gray-Davidson, 1996).
- You could trail behind the person when they are going for a walk -- this will also indicate where they like to go (Gray-Davidson, 1996).
- You can paint a red stop sign on the gate (Gray-Davidson, 1996).
- Remember that walking is calming so try to keep the person with dementia active (Gray-Davidson, 1996).
- Take the person for walks every day (Gray-Davidson, 1996).

2.12 - Hiding and Rummaging

- Conceal doorknobs (Weiner, 1996).
- Provide a drawer in which the person can rummage (Weiner, 1996).
- You can give the person with dementia toy money or a small allowance to avoid hoarding (Gray-Davidson, 1996).

- There is no point in punishing the person for stealing or hoarding because these are memory problems not moral problems (Gray-Davidson, 1996).
- You may wish to have special items that only the caregiver has access to (Gray-Davidson, 1996).
- A study found that taking others possessions could be reduced by cueing a person to understand that a stop sign meant no entry (Opie et al., 1999).

2.13 - Aggression and Sun-downing

- The caregiver should be out of the person's reach rather than ordering self control (Weiner, 1996).
- Simplify the environment (Weiner, 1996).
- Move breakables out of the person's way (Weiner, 1996).

- Use a calm voice and remain calm (Australian Government, 2002).
- Take time out to relax (Australian Government, 2002).
- Avoid punishment because the person may not remember what happened (Australian Government, 2002).
- Understand that the illness, not the person, causes the aggression (Australian Government, 2002).
- "Add an after-lunch nap in to the daily routine" (Gray-Davidson, 1996).
- Alternatively, extend the morning sleeping (Gray-Davidson, 1996).
- Provide an energy producing snack, fruit or cake with a cup of coffee (Gray-Davidson, 1996).
- With sun-downing, provide strong emotional support by sitting with your arm around the person and playing their favourite music (Gray-Davidson, 1996).
- Distract the person from their agitation by producing entertainment such as television or a video (Gray-Davidson, 1996).
- Take a walk or go for a drive to a scenic place (Gray-Davidson, 1996).
- Don't give false consolation for feelings of loss (Gray-Davidson, 1996).
- Reinforce that the person is loved and accepted as they are (Gray-Davidson, 1996).
- Stay calm yourself (Gray-Davidson, 1996).
- "Speak quietly and persistently" (Gray-Davidson, 1996).
- Avoid the overuse of alcohol (Gray-Davidson, 1996).

- Distract: start a new activity, move to another room or leave the house (Gray-Davidson, 1996).
- Ignore anger (Gray-Davidson, 1996).
- You can leave the room but make it clear that you are not leaving as a punishment (Gray-Davidson, 1996).
- Never give orders, just give suggestions; never push roughly, gently guide and never force; do not confront, just persuade (Gray-Davidson, 1996).
- Confrontation and violence will only cause a catastrophic reaction, they will not stop it (Gray-Davidson, 1996).

2.14 - Sexual inappropriateness

- Step away (Weiner, 1996).
- Check that their clothes are comfortable (Gray-Davidson, 1996).
- Remove the person from the situation where the offence is being caused to others (Weiner, 1996).

- Give the person worry beads to keep their hands occupied (Gray-Davidson, 1996).
- Suggest they stop exposing themselves and have a physician check for genital infection etc. or exposure may also be an indication that they need to go to the toilet (Gray-Davidson, 1996).
- Remove their hand and explain calmly that sexual advance is not acceptable (Gray-Davidson, 1996).
- Make their clothes difficult to remove if public undressing is an issue (Gray-Davidson, 1996).
- Don't prevent the person with dementia forming relationships, even sexual relationships with other adults as long as the person is not being abused (Gray-Davidson, 1996).

2.15 - Dressing

- Lay out two sets of clothing to give the person a choice (Weiner, 1996; Gray-Davidson, 1996).
- Beltless trousers are best for men (Weiner, 1996).
- Dresses are best for women (Weiner, 1996).
- Do not confront the person if they prefer different clothes (Weiner, 1996).
- Try telling the person that it is time to change for a special occasion or to go to the doctor (Gray-Davidson, 1996).
- Try saying that you have a new item for the person to wear (Gray-Davidson, 1996).
- As a last resort, spill cold water on the person's clothing to encourage changing, however be prepared for a "catastrophic reaction" (Gray-Davidson, 1996).
- Try to allow as much privacy as possible (Gray-Davidson, 1996).
- Gazing into the distance or wandering away from you suggest that the person wants privacy (Gray-Davidson, 1996).
- Get into a routine as early as possible -- have a set time and place for dressing (Australian Government, 2002).
- Allow lots of time for dressing (Australian Government, 2002).
- Ensure that their clothes are comfortable (Australian Government, 2002).
- After bathing, try handing over each piece of clothing to be put on separately (Australian Government, 2002).
- Allow the person to dress in their own clothes and keep their possessions

(Cummings et al., 2002).

- Explain simply the activity before commencing it (Cummings et al., 2002).

2.16 - Toileting

- Take the person to the toilet at fixed times during the day and remind them to toilet (Weiner, 1996; Australian Government, 2002).
- A two to three hour schedule is usually adequate (Gray-Davidson 1996; Commonwealth Government 2002);
- Times could be marked on a piece of paper and checked by the caregiver until a routine is established (Weiner, 1996).
- Praise successful toileting (Weiner, 1996).
- Cover bathroom mirrors as this may cause the person with dementia to think people are watching them and cause them to urinate etc. in a more private place like a room (Weiner, 1996).
- Provide easily removable clothes (Weiner, 1996) such as clothes with velcro instead of buttons and elastic bands instead of a belt (Australian Government, 2002).
- Running water may help to encourage toileting (Weiner, 1996).
- Keep toilet paper visible and easily accessible (Gray-Davidson, 1996).
- Give reminders and hand out the toilet paper or wipe the person yourself (Gray-Davidson, 1996).
- Buy a pack of thin surgical gloves to use if you have to regularly clean the person after toileting (Gray-Davidson, 1996).
- Carry some spare underwear for change away from home (Gray-Davidson, 1996).
- Also take the person to the toilet before leaving home and after getting back (Gray-Davidson, 1996).
- Do not ask whether the person needs to go to the toilet, just suggest it

(Gray-Davidson, 1996).

- If this is met with denial, tell them to try anyway (Gray-Davidson, 1996).
- Never scold or humiliate the person for incontinence (Gray-Davidson, 1996).
- Incontinence clothing may be useful (Gray-Davidson, 1996).
- Know the person's elimination pattern so you can work with it (Gray-Davidson, 1996).
- Reduce liquids to a minimum at night to reduce bed-wetting (Gray-Davidson, 1996).
- Put plastic under the covers of sofas, chairs and bed sheets (Gray-Davidson, 1996).
- Fold a thick towel over the chair where person's lower body will be positioned (Gray-Davidson, 1996).
- Do not be embarrassed doing extra things for the person as they would have lost their inhibitions (Gray-Davidson, 1996).
- Look to see whether the medications could be causing incontinence or whether other medical problems such as infections are causing it (Gray-Davidson, 1996).

2.17 - Bathing

- Adjust the hot water system so that it is not possible for the person with dementia to burn themselves (Weiner, 1996).
- Non-slip strips, bath seats and grab rails may be installed (Weiner, 1996).
- A hand-held shower head may be useful (Weiner, 1996; Gray-Davidson, 1996).
- Bathe at the time of day the person is used to (Weiner, 1996).
- It may be easier for the person if their spouse showers with them (Weiner, 1996).
- The bath should be prepared beforehand to reduce the need for decision-making (Weiner, 1996).
- Use of a nature scene (rainforest music, sound of flowing water, large bright nature pictures) has been shown to reduce agitation (Opie et al., 1999).
- Do not punish the person for a lack of hygiene as hygiene is not inbuilt -- it is based on standards and memory (Gray-Davidson, 1996).
- At first, gentle verbal suggestions combined with bribes may be enough: "Maybe you'd like to have a shower while I make you a coffee?" (Gray-Davidson, 1996).
- Verbally cue each step of the process where necessary, i.e. cue for undressing, cue for stepping into bath etc. in the same gentle tone (Gray-Davidson, 1996).
- Remember that the person might not associate words with objects so you may need to point at or indicate through touch the object you are referring to (Gray-Davidson, 1996).

- Try to bath instead of shower, try bubble baths (Gray-Davidson, 1996).
- Move your hand in gently upward movements, avoiding face while speaking reassuringly (Gray-Davidson, 1996).
- Try rubbing soapy towel over body to build up trust for bathing process (Gray-Davidson, 1996).
- You may reduce your requirements for bathing (Gray-Davidson, 1996).
- You can encourage person to use baby wipes (Gray-Davidson, 1996).
- You may find a stranger to help with bathing (Gray-Davidson, 1996).
- You can add bathing to the routine before going to visit a favourite friend or relative or before eating (Gray-Davidson, 1996).
- Understand the person with dementia's expectations of bathing.
 - 1. Listen to the person and family members.
 - 2. Observe the person (Sloane et al., 1995).
- Consider the goal of bathing: personal hygiene (Sloane et al., 1995).
- Look at other ways personal hygiene can be achieved other than baths (Sloane et al., 1995).
- Individualise bathing (Sloane et al., 1995).
- Be flexible - if the person shows agitation, try to work out what started it and make changes (Sloane et al., 1995).
- Bed or towel bath are alternatives (Sloane et al., 1995).
- Try to avoid several displeasurable tasks one after another if the person is prone to agitation (Sloane et al., 1995). For example if undressing is upsetting, try bathing first thing in morning so there are less clothes to remove.

- You can use a "beauty parlour" for washing the person's hair (Sloane et al., 1995).
- "Focus on person (feelings and reactions) more than on the task" (Sloane et al., 1995).
- Do not talk to others or listen to the radio (unless the person wants to) -- keep your focus on the person to observe their reactions (Sloane et al., 1995).
- Familiarity is important: use bath products the person used to use where possible (Sloane et al., 1995).
- Be practical in your reasoning to the person with dementia. For example, close the door so flies can't come in (Sloane et al., 1995).
- Respect the person's modesty, privacy and dignity as much as possible. (Sloane et al., 1995).
- Treat the person's perceptions as valid (if they tell you the water is too hot or cold, respond accordingly and change the water even if you disagree with their perceptions) (Sloane et al., 1995).
- If the person is in pain, try to think of anything that could have been uncomfortable for the person - i.e. person's feelings are valid (Sloane et al., 1995).
- Use "persuasion rather than coercion" -- let the person be in control of themselves as much as possible (Sloane et al., 1995).
- You can use padded bath chairs, food items or soft towels as distractions (Sloane et al., 1995).
- Bed baths: you may not need to undress the person all at once. For example you could leave the person's trousers on while you wash their feet (Sloane et al., 1995).

- Undress them slowly and gently (Sloane et al., 1995).
- Allow the person to undress themselves where possible (Sloane et al., 1995).
- Give practical reasons for activities and offer a reward -- "undress so we can get the shower over" (Sloane et al., 1995).
- If verbal prompting is unsuccessful, try gentle physical guidance. (Sloane et al., 1995).
- Try to keep the bath temperature constant. For example you may use foam insulation in bath (Sloane et al., 1995).
- If the person is in pain, pat the areas dry, seek assistance from your GP, make sure nails are cut properly, try sliding thin towel between toes. (Sloane et al., 1995).
- If there is agitation or screaming, stop the task and try to find out from person why they are upset (Sloane et al., 1995).
- Firmly tell the person if they are hurting you (Sloane et al., 1995).
- If they like grabbing at things, do not wear earrings, watches etc. while bathing the person (Sloane et al., 1995).
- If the person is grabbing, distract them with a bath toy or towel to hold. (Sloane et al., 1995).
- Discuss the steps you are taking one by one (Sloane et al., 1995).
- Avoid bathing after meals (Sloane et al., 1995).
- Bowel movement etc. during bathing may be embarrassing for person so toilet before shower (Sloane et al., 1995).

- If it occurs, remain calm and finish the task (Sloane et al., 1995).
- In shower, have the person with dementia step to one side or move the chair (Sloane et al., 1995).
- In the bath, conclude the bath by rinsing their lower body with clean water (Sloane et al., 1995).
- When washing the person's hair place your hand on their hair and let the water run over your hand first to avoid shock or fear to the person (Gray-Davidson, 1996).
- Use a mildly soapy wash cloth (Sloane et al., 1995).
- Use non-rinse shampoo (Sloane et al., 1995).
- Use plugs for their ears (Sloane et al., 1995).
- Wash the person's hair in bed (Sloane et al., 1995).
- Try a scalp massage to relax the person (Sloane et al., 1995).
- The person could have their hair washed at the hairdresser (Sloane et al., 1995).
- You may want to keep hair washing separate to bathing (Sloane et al., 1995).

2.18 - Lighting

- Lighting should be even throughout the room but should be varied throughout the day (Weiner, 1996).
- Use more than just a single lamp (Weiner, 1996).
- Halogen lamps are good (Weiner, 1996).
- Yellows and reds are easier to see for older people and blues and greens are harder to distinguish (Weiner, 1996).
- Use colour to contrast parts of the environment to make them more identifiable. For example, chairs, tables, plates, floor, or walls (Weiner, 1996).

2.19 - Suspicion

- The principle of non-confrontation is most important in dealing with suspiciousness (Weiner, 1996).
- For recognition, dress the same way each day including jewellery and perfume. Firmly say who you are in response to accusations of being a double or someone else (Weiner, 1996).
- Check that the suspicion is really incorrect (Australian Government, 2002).
- Do not move things around the house -- keep familiar things in the same place (Australian Government, 2002).
- Keep spares of items that are often lost such as glasses or keys (Australian Government, 2002).
- Distract the person (Australian Government, 2002).
- "Learn the person's favourite hiding places" (Australian Government, 2002).
- Look for patterns such as who is accused and the time of day it occurs (Australian Government, 2002).

2.20 - Eating

- Keep the same eating places and routines (Weiner, 1996).
- Give the person a choice but reduce the number of choices (Weiner, 1996).
- Use the sound of plates etc. to show that it is time for meals (Weiner, 1996).
- Have the person checked for gum and mouth problems (Australian Government, 2002).
- Feed the person small meals frequently (Weiner, 1996).
- If the person refuses the food, take it away and put it on another plate (Weiner, 1996).
- Non-food items should be kept separate so they are not consumed (Weiner, 1996).
- Keep the table setting simple and familiar -- i.e. do not change the seating arrangements (Weiner, 1996; Australian Government, 2002).
- Provide plenty of finger food (Weiner, 1996; Australian Government, 2002).
- Provide culturally appropriate food (Weiner, 1996).
- Suggest things tactfully rather than asking what the person wants (Gray-Davidson, 1996).
- Put food before the person even if the person says they don't want it (Gray-Davidson, 1996).
- Don't force the food issue (Gray-Davidson, 1996).

- If the person really won't eat, try protein shakes (Gray-Davidson, 1996).
- Be flexible with serving food -- you may serve dessert first (Australian Government, 2002).
- Obtain medical or speech therapy support for swallowing or chewing issues (Australian Government, 2002).
- High fibre intake, fluid and appropriate exercise are preferable to laxatives because laxatives increase the need for toileting, which in turn increase the urgency of movement leading to a greater risk of falling (Weiner, 1996).

2.21 - Safety

- Safety may include "child-proofing" the house (Gray-Davidson, 1996).
- All stoves should be off, especially if the person is alone (Gray-Davidson, 1996).
- Remove all hazards including loose rugs etc. (Gray-Davidson, 1996; Australian Government, 2002).
- Turn down the water temperature of the hot water system (Gray-Davidson, 1996).

2.22 - Tips for Distracting

- Play simple games (Weiner, 1996).
- Walk (Weiner, 1996).
- Play the person's favourite music (Weiner, 1996; Ballard et al., 2001; Gray-Davidson, 1996; Opie et al., 1999).
- The listener should be given control over the volume, duration and type of music played (Ballard et al., 2001).
- The use of music, videos and social interaction has been shown to reduce shouting and repeated attention seeking (Opie et al., 1999).
- The use of single sounds such as a flowing brook has also been shown to reduce agitation (Opie et al., 1999).
- Playing tapes or recounting family stories and anecdotes has also been also successful (Opie et al., 1999).
- "Reminiscence therapy" is useful -- it helps the person relive and think about positive past experiences and can be done through art, music, and photos (Ballard et al., 2001).
- Use diaries and videos (Ballard et al., 2001).
- Regular exercise is important -- it aids sleep, improves mental health, and reduces falls, prevents isolation and benefits confidence and mood (Ballard et al., 2001; Gray-Davidson, 1996; Wiscott et al., 2001; Opie et al., 1999).
- Dance (Ballard et al., 2001; Gray-Davidson, 1996).
- Aromatherapy may also be useful, depending on whether the person's sense of smell still remains, as smell is lost early in the course of dementia (Ballard et al., 2001).

- Coffee, lemon and lavender can be detected in later stages. It is therefore suggested that lavender and lemon balm may be used as they have a calming effect (Ballard et al., 2001; Burns et al., 2002).
- Light therapy (using a light box to provide extra light, particularly in the morning) has been found to be beneficial (Burns et al., 2002; Opie et al., 1999).
- Artwork, colouring book or painting (Gray-Davidson, 1996).
- Clay work (Gray-Davidson, 1996).
- Reading books to the person (Gray-Davidson, 1996).
- They may try reading alone or sitting with a book (Gray-Davidson, 1996).
- Illustrated books may be good. For example travel or animal books (Gray-Davidson, 1996).
- Try children's picture books (Gray-Davidson, 1996).
- Poetry (Gray-Davidson 1996).
- Taped books work for some people (Gray-Davidson, 1996).
- Attend story-telling performances at libraries (Gray-Davidson, 1996).
- Giving the person a massage (Opie et al., 1999).
- Supervise the person while they cook (Gray-Davidson, 1996).
- Look at children's cookbooks -- cookies are good idea (Gray-Davidson, 1996).
- Take the person with dementia for a drive (Gray-Davidson, 1996).

- Exercise (keep in mind the person's ability) (Gray-Davidson, 1996).
- Yoga and tai chi (Gray-Davidson, 1996).
- Finger work cutting up cards, folding, sorting, polishing etc. (Gray-Davidson, 1996).
- You may extend the task (carrying folded towels away and bringing them back unfolded and asking them to be folded again) (Gray-Davidson, 1996).
- Simple or familiar games (Gray-Davidson, 1996).
- Building blocks (Gray-Davidson, 1996).
- Matching picture games (Gray-Davidson, 1996)
- Gardening (if there is a concern about eating plants, use only edible ones) (Gray-Davidson, 1996).
- Housework: wiping surfaces, washing up, folding clothes (lower your standards with housework to enable help) (Gray-Davidson, 1996).
- Hugging (Gray-Davidson, 1996).
- Simple jigsaw puzzles (Gray-Davidson, 1996).
- Going to the movies. Make a with careful choice with optimistic easy to follow films (cartoons are not good). Take lots of snacks and ensure a lot of physical contact (Gray-Davidson, 1996).
- Pets, especially try for adult animal as younger animals may be disruptive and cause stress (Gray-Davidson, 1996).
- Looking at photographs (Gray-Davidson, 1996).

- Shopping (but success varies) (Gray-Davidson, 1996).
- Try a coffee shop or ice creamery (Gray-Davidson, 1996).
- Sight seeing (Gray-Davidson, 1996).
- Socialise. The carer should point out to visitors how much pleasure the person gained from their visit so as to encourage them to come again. (Gray-Davidson, 1996).
- Television in small amounts (Gray-Davidson, 1996).
- Children's shows or comedies may be good (Gray-Davidson, 1996).
- Avoid news, fast-moving programs, violent programs or cartoons (Gray-Davidson, 1996).
- Toys, especially stuffed animals, simple puzzles or soft balls (Gray-Davidson, 1996).
- Toys for children aged 2-5 may be best for severely demented people (Gray-Davidson, 1996).

References

- Australian Government. (2002). *The carer experience: An essential guide for carers of people with Dementia*. Department of Health and Aging: Commonwealth of Australia.
- Ballard, C.G., O'Brien, J., James, I., & Swann, A. (2001). *Dementia: Management of Behavioural and Psychological Symptoms*. Oxford: Oxford University Press.
- Betts Adams, K., & Sanders, S. (2004). Alzheimer's caregiver differences in experience of loss, grief reactions and depressive symptoms across stage of disease. *Dementia*, 3, 195-210.
- Bowlby Sifton, C. (2004). *Navigating the Alzheimers Journey: A compass for caregiving*. Baltimore, USA: Health Professionals Press.
- Coon, D.W., Gallagher-Thompson, D., & Thompson, L.W. (2003). *Innovative interventions to reduce dementia caregiver distress*. New York: Springer Publishing Company.
- Cummings, J.L., Frank, J.C., Cherry, D., Kohatsu, N.D., Kemp, B., Hewwett, L., & Mittman, B. (2002). Guidelines for Managing Alzheimer's Disease: Part II. Treatment. *American Family Physician*, 65, 2525-2533.
- Davidson, F.G. (1996). *The Alzheimers sourcebook for caregivers*. Los Angeles: Lowell House.
- Fritz, C.L., Farver, T.B., Hart, L.A., & Kass, P.H. (1996). Companion animals and the psychological health of Alzheimer patients' caregivers. *Psychological Reports*, 78, 467-481.
- Gray-Davidson, F. (1996). *The Alzheimer's Sourcebook for Caregivers: A practical guide for getting through the day*. Los Angeles: Lowell House.
- Gitlin, L.N., Corcoran, M., Winter, L., Boyce, A., & Huack, W.W. (2001). A randomized, controlled trial of a home environmental intervention: Effect on efficacy and upset in caregivers and on daily function of persons with dementia. *The Gerontologist*, 41, 4-11.
- Holroyd, S. (2004). Managing dementia in long-term care settings. *Clinics in Geriatric Medicine*, 20, 83-92.
- Jones, S.N. (1995). An Interpersonal Approach to Psychotherapy with Older Persons with Dementia. *Professional Psychology: Research and Practice*, 26, 602-607.

- Le Navenec, C., & Vonhof, T. (1996). *One day at a time: How Families Manage the Experience of Dementia*. Connecticut: Auburn House.
- Marriott, A., Donaldson, C., Tarner, N., & Burns, A. (2000). Effectiveness of cognitive-behavioural family interventions in reducing the burden of care in carers of patients with Alzheimers disease. *British Journal of Psychiatry*, *176*, 557-562.
- Opie, J., Rosewarne, R., & O'Connor, D.W. (1999). The efficacy of psychosocial approaches to behaviour disorders in dementia: A systematic literature review. *Australian and New Zealand Journal of Psychiatry*, *33*, 789-799.
- Patterson, T.L., & Grant, I. (2003). Interventions in dementia: Physical outcomes. *Current Opinion in Psychiatry*, *16*, 629-633.
- Schmidt, G.L., Bonjean, M.J., Widem, A.C., & Schefft, B.K. et al. (1988) [Brief psychotherapy for caregivers of demented relatives: Comparison of two therapeutic strategies.](#) *Clinical Gerontologist*, *7*(3-4), 109-125.
- Sloane, P.D., Rader, J., Barrick, A., & Hoeffler, B. et al. (1995). Bathing persons with dementia. *The Gerontologist*, *35*, 672-678.
- Slone, D.G., & Gleason, C.E. (1999). Behavior management planning for problem behaviors in Dementia: A practical model. *Professional Psychology: Research and Practice*, *30*, 27-36.
- Small, J.A., Gutman, G., Makela, S., & Hillhouse, B. (2003). Effectiveness of communication strategies used by caregivers of persons with Alzheimer's disease during activities of daily living. *Journal of Speech, Language and Hearing Research*, *46*, 353-367.
- Teri, L., Logsdon, R.G., Whall, A.L., Weiner, M.F., Trimmer, C., Peskind, E., & Thal, L. (1998). Treatment for agitation in dementia patients: A behaviour management approach. *Theory, Research, Practice, Training*, *35*, 436-443.
- Vitaliano, P.P., Zhang, J., & Scanlan, J.M. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin*, *129*, 946-972.
- Weiner, M.F. (Ed.) (1996). 2nd ed. *The Dementias: Diagnosis, management and research*. Washington, DC: American Psychiatric Press.
- Wiscott, R., Kopera-Frye, K. & Seifert, L. (2001). Possible Consequences of Social Drinking in the Early Stages of Alzheimers Disease. *Geriatric Nursing*, *22*, 100-105.

Useful Resources

Organisations - Telephone numbers

Alzheimers Association of Queensland - 3857 4043
The Dementia Helpline - 1800 639 331
The Commonwealth Carers Resource Centre - 1800 242 636
The Department of Veterans Affairs - 13 3254
Centrelink - 13 2717 (Disability number)

Websites

Alzheimers Australia - www.alzheimers.org.au
Alzheimers Association of Queensland - www.alzheimers.online.org
The Carers Resource Centre - www.carersqld.asn.au
The Department of Veterans Affairs - www.dva.gov.au
Centrelink - www.centrelink.gov.au

Books

Coon, D.W., Gallagher-Thompson, D., & Thompson, L.W. (2003).
Innovative interventions to reduce dementia caregiver distress.
Springer Publishing Company: New York.
Sifton, C. (2004). *Navigating the Alzheimers Journey: A compass for
caregiving*. Health Professionals Press: Baltimore, USA.

Journals

Brodaty, H., Draper, B.M., & Low, L. (2003). Behavioural and
psychological symptoms of dementia: a seven-tiered model of service
delivery, *MJA*, 178, 231-234.
Burns, A. (2000) The burden of Alzheimer's disease. *International Journal
of Neuropsychopharmacology*, 3 (Suppl. 2), S31-S38.
Farran, C.J., Loukisa, D. Perraud, S., & Paunz, O. (2004) Alzheimer's
Disease Caregiving Information and Skills. Part II: Family Caregiver
Issues and Concerns. *Research in Nursing & Health*, 27, 40-51.
Glueckauf, R.L., & Loomis, J.S. (2003). Press Alzheimer's Caregiver

Support Online: Lessons learned, initial findings and future directions. *NeuroRehabilitation* 18, 135-146.

Logiudice, D. (2002). Clinical Perspectives Dementia: an update to refresh your memory. *Internal Medicine Journal*, 32, 535-540.

Understanding and Caring for the Person with Dementia: A Practical Guide for Caregivers is written primarily for family members caring for a loved one. It is also useful for training staff and volunteers who provide care in nursing homes, hospitals, adult day centers, assisted living facilities and private homes. The basic caregiving techniques are similar, regardless of the setting. Chapter 2 offers practical caregiving tips including suggestions for communicating with the person with dementia. Chapters 3 and 4 focus on daily activities and managing behavioral problems. Chapter 5 addresses the impact of dementia on the family and provides information to help caregivers cope with the emotional issues they may face. Estimates of the proportion of people with dementia who live in care facilities range from 19% [5] to 49% [6] meaning there are many informal carers e.g. family members and friends assuming the role of primary carer for their loved ones. Research suggests that carers of people with dementia often display poor health as compared to their age-matched peers [7] and therefore require as much assistance as possible to be able to support PWD while maintaining their own well being. Dementia Australia provides a practical guide for carers of PWD. References: National Health Service; Pinquart M, Sorenson S. Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis *Psychology and Aging*. 2003; 18(2): 250-67. Caring for someone with Alzheimer's or dementia can be extremely stressful. These tips can help you cope and get the support you need. This guide will help you prepare for the caregiving road ahead and get the help you need. The Alzheimer's and dementia care journey. Caring for someone with Alzheimer's disease or another type of dementia can be a long, stressful, and intensely emotional journey. In the United States, there are more than 16 million people caring for someone with dementia and many millions more around the world. As there is currently no cure for Alzheimer's or dementia and only limited medical treatments available for the symptoms it is your caregiving that can make the biggest difference to your loved one's quality of life. That is a remarkable gift.