

## INCONTINENCE AND DEMENTIA: Providing Innovative Family Care

### INTRODUCTION

*'I think that the incontinence is probably the worst thing, she didn't have any control over her bowels. I found it everywhere because she was trying to hide it. Even when you were changing her she would be doing it while you tried to change her. I found it in the drawers as well. It was all on the clothes in the drawer. She was obviously trying to hide it.'* (Armstrong 1999:19)

### What is the issue?

Generally the Western world is experiencing an increasing trend for families and other caregivers to support older people residing at home in the community (Commonwealth Dept of Health and Aging care 2000). Many older people who require care in the home environment have dementia illnesses with an aligning physical disability of incontinence. These diagnoses however, are usually only a part of the complex needs that caregivers contend with. The main source of informal care provided to these individuals is spousal (Australian Bureau of statistics 1998) and as demand generally outstrips resources, the combination of cognitive impairment and incontinence may be one of the eventual predictors for institutionalisation (15, 8). The vast majority of caregivers are "informal caregivers", ie unpaid persons. Most caregivers are spouses, but family members and friends can also be caregivers.

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**The Research Unit is proudly supported  
by the RDNS Foundation.**

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### What is the prevalence?

The prevalence of incontinence for Australians differs dramatically according to the source, but has been approximated as 800,000 in 1995 (16), while in 2005 the condition is thought to affect approximately 1:20 or 2 million people. The ratio of incontinence for people who also have dementia is relatively unknown (16) although Ouslander et al 1990 identified two studies, which revealed a prevalence rate of 23–53 % of older people living in the community as also reporting incontinence. Given the ageing population it can also be surmised that dementia will become increasingly relevant to health services, policy makers and the Australian community. There are approximately 18,200 people newly diagnosed with dementia annually, with around 9,900 people aged under 60 years also having the condition. During 2005, it is estimated that 200,000 people have dementia with incontinence. Dementia care in Australia is provided in a range of different settings, the most frequent being community (residential) settings (80%) and nursing home environments (20%). Thirty percent of RDNS (SA) clients (approximately 800) have a varying degree of dementia. Of these, 40% have mild dementia, 46% have moderate dementia and most interestingly 14% are at the cusp of moderate to severe dementia (Visentin *et al* 2002). Ninety percent of RDNS clients with dementia live alone. Clearly, community nurses have an important role to play in the lives of people living in the community with dementia.

Dementia is a decline in intellectual ability to the point that it interferes with social or occupational functioning. The medical diagnosis of dementia denotes many diseases (more than twenty) or disorders that have a cumulative and degenerative affect on the normal neurological pathways of the body (3). Sticky plaques and clumps of tangled fibres gradually spread through the brain resulting in a loss of cognitive functioning which is progressive, irreversible and degenerative. Incontinence is not an inevitable result of dementia (9) but may occur due to the inability to interpret normal bodily cues, the loss of recognition of toileting facilities and appropriate social responses to disinhibition and continence (8, 11, 14), yet dementia and functional impairment are frequently associated and the link between dementia and incontinence has been demonstrated in multiple studies and professional papers. The combination of conditions is often considered a usual but not inevitable consequence of progressive disease.

The focus of this newsletter is to discuss evidence-based considerations, techniques and insights on how to support caregivers of people living in the community with dementia and incontinence.

### What are the impacting issues for caregivers?

Care giving can be extremely stressful yet the caregiver burden has not been quantitatively or qualitatively measurable on any test or scale. Inevitably each person's coping abilities are different and there are sometimes cultural taboos that prohibit caregivers from expressing that a problem exists or from accepting help; to do so would be to admit failure. A community nurse's support can be invaluable. Themes that emerge from conversations with carers relate to clean up operations, the changing nature of the house, use of toilets as indicating competence and embarrassment about incontinence (8). The social implications and stigma attached to incontinence is often the reason that people seek help. A high standard of personal hygiene is an expectation in our society and adults are expected to have control over elimination. For people caring for a person with dementia and incontinence, the mundane routines for managing continence take on a greater importance as incontinence intrudes into their lives. Caregivers are confronted with a range of physical and psychosocial demands that challenge them as spouses, human beings and caregivers (often with minimal professional assistance). The term "caregiver burden" refers to a people's emotional response to changes and demands that occur as they give help and support to the older person. A representation of some of the challenges that caregivers have reported are listed below:

### Economic

Families will often try to 'go it alone' and purchase inappropriate and costly products from supermarkets and chemists without the benefit of a holistic and multifocal

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assessment to determine need and appropriate products. Within South Australia there is no scheme for people aged over 65 to purchase disposable pads, and so places a caregiver the burden of significant consequence on the limited and often fixed finances of older people. Coupled with this additional burden is the continued and rising cost of everyday living and health needs for the caregiver and receiver, which often go unremarked, with the focus remaining on the need to provide continence products to contain an ever-worsening problem. Often unnoticed and unreported is the increased housework, laundry, need for additional clothing/linen and possibly the need to replace household furniture/floor coverings due to repeated soiling.

The general cost of maintaining the care receiver at home does not often consider the possible need for home modifications, laundering, lost income for the caregiver and other routine care. Statistics reveal that containing incontinence for older people is big business. In 2001, continence costs for America and Italy accounted for 2% of the total health budget with Italians spending approximately US\$1000 per year, per person aged over 65 on incontinence pads alone (2).

## *Adverse health effects*

Spousal caregivers are generally of the same differential age as the care receiver and therefore often suffer from their own health issues, which can be exacerbated by the additional burden of containing incontinence. A variety of studies during the last two decades reveal that that this factor contributes as much as incontinence to perceived caregiver burden and often leads to caregivers to think of alternative methods of care provision.

## *Quality of life*

Changes to quality of life have a significant impact on both the carer and the care receiver. The caregiver is often embarrassed by the person's behaviour, and may be reluctant to take the person out in public, hence both of them can become prisoners in the home. Impacting on quality of life can include social isolation, decreased finances, adverse quality of familial relationships associated with the shift of care to younger members of the family who are unable or unwilling to provide assistance to the primary caregiver, and adverse health outcomes for the caregiver (9, 4, 7).

The relationship between caregiver and the person with dementia may also change, particularly when the caregiver is a spouse. A significant loss of intimacy can result from both the physical manifestation of incontinence and the pathology of dementia as the sufferer can misinterpret normal sexual advances and the caregiver may be repulsed by the actuality of intercourse with a sufferer of incontinence. However one report demonstrates that hugging and kissing may increase as sexual intimacy decreases (2).

## *Loss of sleep*

Loss of sleep rates highly in the caregiver burden scale with many carers stating that they seem never to escape the burden over a 24 hour period as they are woken multiple times during the night to toilet or change the linen of the care receiver. A loss of rest and sleep can lead to an increase in the other areas of burden. Spouses and family members giving care to a person with dementia are nearly twice as likely to have symptoms of depression compared with caregivers of non-demented people. They also have higher rates of chronic illness and are twice as likely to be using psychotropic medications for depression or anxiety as people who are giving care to someone without dementia (Canadian Study of Health and Aging).

## *Physical complications*

A result of attempting to manage urinary and/or faecal incontinence over a sustained period of time may mean that caregivers find their level of expertise challenged to the point of exhaustion. Often the incontinent individual will also have urinary tract infections, sleeping difficulties, depression, skin problems and pressure sores. All of these complications may compound the caregiver burden and may singly or collectively add to the decision to institutionalise the individual.

## *Disruptive behaviour*

The nature of dementia means that the caregiver is confronted by disruptive or aggressive behaviour related to toileting the care receiver (11). A full assessment of the care receiver will help to determine the cause of this behavioural change, as it may not be the dementia that is causing the behaviour and once treated appropriately, the behaviour may resolve. In the event that the behaviour is directly related to the dementia the GP will be able to refer the caregiver on to an Aged Care Mental Health agency who will be able to provide the appropriate support and interventions to

deal with the uncooperative person. For caregivers, coping with behavioural changes may be a reason that they seek alternative care provisions (2). However, there are also protective factors that may help reduce the likelihood of caregiver burden. These include:

- help from other family members,
- the ability to use problem-focused coping strategies,
- availability of support from the community.

While there is a focus in the literature on the negative consequences of care giving, there is also evidence that there may be benefits, by improving the relationship between caregiver and care receiver, and giving the caregiver a feeling of being useful (Schulz et al 1990, Nolan et al 1996, Wells and Kendig 1997). Nolan et al 1996 focused on the positive aspects of family care giving and found that family relationships can be enhanced through expressions of appreciation, love and affection, a sense of dignity and achievement, reduction of guilt, development of personal qualities such as tolerance and patience, development of skills and abilities in caring and existential satisfaction. Community nurses can play a pivotal role in promoting these positive aspects of care giving.

## **What are some community nursing interventions to consider?**

The expectation and right of every individual to have a full continence assessment if they choose is valid. The management plan for those with a cognitive impairment should encompass realistic aims that can be implemented within the environment and ultimately seeks to benefit the client (12). The level of cognitive ability will be a significant predictor of success with scheduled training programs. For individuals with a greater degree of impairment other methods will need to be employed.

It is important to note that comfort and dignity rate highly in any management plan (6,11) and the caregiver is generally the best judge of the care receivers capabilities and limitations. A primary health care perspective of working 'with' people to plan care becomes profoundly important. To set an individualised management plan it is vital to have a thorough nursing, medical and pharmacological, holistic and multifactorial assessment. Employ the knowledge from all those

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professional and social individuals that have a key stake hold in the care receivers health and welfare. Here are some innovative nursing care considerations that may help to minimise caregiver burden:

- Review modifiable risk factors that may exacerbate incontinence such as:
    - Recurrent urinary tract infections
    - Constipation
    - Poorly controlled diabetes
    - Delirium (un sourced infection)
    - Hypertension
    - Parkinsonism
    - Arthritis
    - Pain
    - Functional mobility issues
    - Hearing/visual impairments
    - Medications (antidepressants, benzodiazepines, diuretics, hypnotics, tranquillisers)
    - Smoking
    - Alcohol
    - Obesity
    - Fluid intake (caffeine, poor intake level)
  - Develop knowledge of the care receiver's toilet cues (fidgeting, getting up and down multiple times, repeating the same word, attempting to remove clothing, agitation and wandering).
  - Consider providing the caregiver with voiding, bowel and food journals to appropriately map input and output over a designated period of time. The journals will enable the nurse to know when incontinence occurs in relation to other events such as medications, bedtime, change of carer, food and drink intakes and at times of exercise or exertion.
  - Physical assessment to determine pelvic floor strengths and eliminate other co-morbidities that could impact on toileting programs such as haemorrhoids, vaginal or rectal prolapse, thrush, vaginitis, poor pelvis lift, or hernias.
- Develop a management plan with the individual, caregivers and if possible include the wider family unit. The management plans will need to be revisited and revised at regular intervals. Include some key factors in the plan:
- Ensure adequate daily fluid intake, approximately 5-8 glasses of a variety of fluids (jelly, ice cream and custard are appropriate), balanced evenly across the day. People with dementia

are often reluctant to drink and gentle encouragement at favourite times of day and a greater variety of fluids can be explored.

- Review the caffeine intake in both food and fluid and endeavour to inhibit after 16.00 as this can reduce the effect on nocturia. A trial of decaffeinated tea and coffee could also be of benefit.
- Trial a toileting routine for bowel management – make use of the morning gastro-colic reflex following this effective routine for bowel evacuation. For example, encourage the individual to eat an orange after getting up in the morning followed shortly after by breakfast and a warm drink. Twenty minutes later encourage the person to sit on the toilet for no more than ten minutes.
- Ensure clothing is loose and easy to access – encourage the use Velcro instead of zippers – consider elastic waisted garments and always change wet clothing.
- Ensure that the containment products used meet the needs of both the caregiver and receiver and that a supply is easily obtainable at the lowest possible cost. Where appropriate seek out sources of funding. Have the carer trial a wide variety of products before purchasing in any bulk.
- Skin care must be maintained in an optimal condition to ensure that further complications eg pressure sores, thrush, skin breakdown are minimised. Whenever the care receiver is soiled, wet or incontinent then the area should be washed, dried and barrier cream applied.
- Learn of the resources and community supports available. Aids to functional incontinence may assist in allowing the care receiver to regain a greater degree of continence than previously thought possible. Aids can be obtained through Independent Living Centres, Aids and Equipment suppliers, wholesalers and Domically Care organisations. Typically equipment may consist of grab rails, toilet raise, walker, urinals and bedpans (1).
- One of the key factors in the toileting and continence of people with dementia is the toileting environment. This becomes particularly important when the individual has lost insight and awareness to rationalise where they are and whether the place they are in is

even a toilet. Ensure the toileting facility is well lit, clean, warm, private, within reach of their functional ability and uncluttered from items that the sufferer may mistake for a toilet.

- Review dietary intake to ensure that a healthy amount of fibre in relation to the individuals general health and body weight is being consumed daily. An increase or decrease may be required, however if fibre is increased then a commensurate increase of fluids should also occur. The provision of a stool journal will help the nurse to assess the efficacy of this program and make planned alterations as needed.
- Falls are considered a potential consequence of dementia and incontinence secondary to other health complications such as urinary tract infection, loss of mobility, urge incontinence, disorientation, loss of spatial awareness and hypotension. To ensure the safety of individuals it is important to have regular health and medication checks and to be aware of signs and symptoms that are indicative of an impending fall. This could include agitation, dizziness, or being over eager to get to the toilet. It is also prudent for those individuals that have recognition cues that the route to the toilet is clear, signposted and well lit.
- Be wary of being too eager for the easy 'medication fix' as potentially many medications have the ability to cause or contribute to both urinary and faecal incontinence – even those labelled as 'natural' or available over the counter.
- Allow time and space for carers and family to regain control of a situation that will periodically feel overwhelming. Providing them with a strategic management plan may indeed ameliorate carer stress levels and postpone institutionalisation. Provide carers and family members with written, oral and visual information whenever possible to guide and support them towards achieving improved lifestyle outcomes for the sufferer and themselves.
- Provide encouragement and support. Help the caregiver and the individual to see and celebrate the 'wins' rather than a continual problem focus. Help the person giving care to establish personal boundaries and develop reasonable expectations of the care receiver, and of him or herself.

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## Conclusion

Embarrassment, frustration, fear and social stigma prevent many people from discussing incontinence. People often fail to seek information and immediate help for the problem. Individuals and caregivers, therefore, miss out on opportunities for an early assessment and diagnosis. Incontinence, in many instances, can be successfully treated, managed or even cured.

It is important to consider the impact of a dementia diagnosis on the structural, physical and psychological wellbeing of any family unit. Incontinence compounds the turmoil that a family experiences and it is a testimony to caregivers that they surmount the burdens. Continence management, including toilet assistance, can be a major cause of caregiver burnout.

Nursing interventions need to be clinically effective and should take account of what carers need and not what nurses think they need. We have a duty of care to examine each individual situation and develop innovative, creative and enlightened health care plans to contain the consequences of incontinence and dementia.

## REFERENCES

1. Calkins M, Namazi K (2000). Caregiver's perceptions of the effectiveness of home modifications for community living adults with dementia. (US) Pages 1-2.
2. Cassells C, Watt E, (2003). The impact of incontinence on older spousal caregivers. *Journal of Advanced Nursing (Australia)* Pages 2-4,7-8,10.
3. Clarke C, (1995). Incontinence and dementia: A combination with consequences. *The Australian Continence Journal (Australia)*. Pages 6-8.
4. Clemensha L, Davies E (2004). Educating home carers on faecal incontinence in people with dementia. *Nursing standard (UK)*. Pages 33-35, 38-40.

5. Colling J, Owen T, McCreedy M, Newman D (2003). The effects of a continence program on frail aged community dwelling elderly persons. *Urologic nursing (US)*. (117) Pages 1,3.

6. Doody RS, Stevens JC, Beck C et al (2001). Review: Pharmacological and non-pharmacological interventions improve outcomes in patients with dementia and their caregivers. *EBMM (US)*. Page 199.

7. Flaherty J, Miller D, Coe R (1992). Impact on caregivers of supporting urinary function in non-institutionalised chronically ill seniors. *The Gerontological society of America (US)*. Page 541.

8. Forbat L (2004). Listening to carers talking about the subject of continence and toileting. *Nursing Times (UK)*. 46 pp2, 49 pp4.

9. Holroyd-Leduc J, Tannenbaum C (2005). *Geriatrics and Aging (Canada)*. Dementia: Incontinence in long-term residents with dementia. Pages 53-58.

10. Hunsakker S, Ostbye T, Borrei M (1998). The prevalence of urinary incontinence in elderly Canadians and its association with dementia, ambulatory function and institutionalisation. *Norwegian Journal of Epidemiology (Norway)*. Page 177-178 pp2-3.

11. Jirovec M, Templin T (2000). Predicting success using individualised scheduled toileting for memory impaired elders at home. *Research in Nursing and Health (US)*. Page 2,7.

12. Murray M, Cockerell R (1995). Incontinence in the cognitively impaired – a functional evaluation. *The Australian Continence Journal (Australia)*. Page 16 pp2,4,6.

13. Noelker L (1987). Incontinence in elderly cared for by family. *Gerontologist (US)*. Page 194,199,200.

14. Ouslander J, Zarit S, Orr N, Muria S (1990). Incontinence among elderly community dwelling dementia patients. *American geriatric society (US)*. Page 440,443,444.

15. Phillippe T et al (2004). Reasons of informal caregivers for institutionalising dementia patients previously living at home: The Pixel study. *International Journal of geriatric Psychiatry (France)*. Page 130-131.

16. Vucic N (1995). Difficulties associated with the management of urinary incontinence in the cognitively impaired. *The Australian Continence Journal (Australia)*. Page 10,12.

17. Canadian Study of Health and Aging. (1994) Patterns of caring for people with dementia in Canada. *Canadian Journal on Aging*, 13(4), 470–487.

18. Armstrong M. (1990) Factors affecting the decision to place a relative with dementia into residential care, *Nursing Standard* 14,16 pp. 33-37.