National Continence Management Strategy

Faecal Continence Grants Program

Final Project Report

Improving and Maintaining

Faecal Continence in People

with Dementia

Being Cared for at Home

December 2002
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PROJECT SUMMARY

This project focused on people with dementia being cared for at home, amongst whom loss of faecal continence is a major factor in eventual institutionalisation. It provided individual faecal continence assessment and care planning, carer education and support in maintaining faecal continence and ongoing monitoring of outcomes. The project required full-time employment of a continence advisor and the production and implementation of specific carer focused educational resources. Project evaluation was ongoing and summative. The project was a collaborative venture between the School of Nursing (Queensland) Australian Catholic University and Blue Care Continence Advisory Service (Brisbane Central Region).

The project was conducted from January to December 2002 by the Project Team (Appendix 1). It comprised four stages: project preparation; assessment and care planning; carer education; implementation and monitoring. There was some overlapping of stages and project evaluation occurred throughout.

Project preparation involved recruitment of participants into the project, production of educational resources, development and piloting of assessment, planning and monitoring documentation and development of evaluation instruments. The expertise of the project team was heavily utilised to assist the project officer during this stage. Participants were recruited from a number of sources including domiciliary nursing and respite services. Recruitment included provision of information to participants and obtaining written consent. Educational resources for carers were also produced during this stage. A sixteen-minute videotape was commercially produced, with the project team acting as content advisors. Printed educational materials were prepared to supplement the videotape. Faecal continence assessment, planning, and monitoring documentation was prepared by the project team for the specific purposes of the project. Evaluation instruments were also prepared at this stage.

Assessment of each individual recruited into the project was then carried out by the Project Officer. This assessment occurred in the home setting, at the convenience of the home carer. Planning, based on an analysis of assessment data for each person with dementia, was then completed. Each plan indicated the actual or potential problems identified, strategies to be implemented, expected outcomes and monitoring requirements. Project evaluation commenced at this stage with the aggregation of assessment data to provide a pre-intervention profile of the people with dementia, factors associated with potential problem development and the nature and frequency of their faecal continence problems. Carers were also surveyed to ascertain their knowledge of promoting and maintaining faecal continence and to determine their experience of caregiving.

Carer education was then commenced by providing each home carer with a copy of the educational videotape. The Project Officer followed up with discussion and clarification and provided the home carer with supplementary printed educational materials. Prior to commencement of planned interventions,
and at any subsequent time, the project officer was available to reinforce existing concepts or introduce new information, as indicated. Each home carer was assured of the ongoing support of the Project Officer throughout the project. **Project evaluation** involved repeat completion of the survey of carer knowledge three months after implementation of planned interventions, for comparison with pre-education data.

**Implementation** of the planned interventions by the home carer for each individual was then commenced. The Project Officer visited each household at regular intervals over the three month implementation period to ascertain support needs, **monitor** actual outcomes against expected outcomes, revise plans if indicated and keep appropriate records. **Project evaluation** was continuous throughout this stage. Aggregated data of the participant profile, factors associated with potential problem development and the nature and frequency of faecal continence problems was collected and collated for comparison with pre-intervention data. The Experience of Caregiving Questionnaire was again completed towards the end of the implementation stage for comparative purposes.

**Project evaluation**, commenced early in the project, was then completed. This provided pre and post intervention measures of: participant profile, factors associated with problem development and faecal continence problems; home carer understanding of promoting and maintaining faecal continence; and information on the experience of caregiving.

This final report describes the project, presents pre and post intervention results and makes recommendations for best practice in promoting and maintaining faecal continence in people with dementia being cared for at home.
1.0 BACKGROUND TO THE PROJECT

This project was directed towards better home management of faecal continence for people with dementia. This project targeted people with dementia being cared for at home and their primary carer.

1.1 Project Objectives

The following objectives have provided direction for the project:

- to maintain / improve levels of faecal continence in people with dementia;
- to educate and support home carers in enhancing faecal continence;
- to produce carer focused educational resources.

This early intervention approach aimed to prevent / delay institutionalisation of people with dementia by improving and maintaining faecal continence through:

- initial and ongoing individual assessment of faecal continence;
- identification of actual and potential faecal continence problems for each individual;
- individual planning of interventions to correct / prevent problems and enhance existing capacities;
- education of home carers in faecal continence management techniques; and
- evaluation of project effectiveness.

1.2 Expected Outcomes

The project was expected to result in:

- identification of the frequency and nature of actual and potential faecal continence problems that exist amongst people with dementia being cared for at home;
- validation in practice of the efficacy of an early intervention program to ameliorate these problems; and
- the production of widely applicable carer focused educational resources on maintaining faecal continence.

1.3 Expected Benefits

The following benefits were expected to accrue from the project:

- increased knowledge of the types and nature of faecal continence problems amongst people with dementia being cared for at home;
recommendations for best practice in the promotion and maintenance of faecal continence in this cohort;
• better understanding among home carers;
• reduction in carer stress and burden associated with home care of a person with dementia;
• enhancement of dignity in the carer / dementia sufferer relationship; and
• availability of carer focused educational materials that can be widely disseminated and adapted for multi-media.

2.0 PROJECT RELEVANCE

The Australian Bureau of Statistics (ABS) indicates that the proportion of the Australian population aged 65 and over has increased from 4% in 1901 to 12% in 2001 (Commonwealth Department of Health and Aged Care, 2002). Five per cent of people over 65 have some form of dementia, with the rate rising to 20% in people over the age of 80. Current predictions estimate a total of 258,000 persons with dementia in Australia by 2021 (Commonwealth Department of Health and Aged Care, 2000).

Dementia is an umbrella term for diseases or disorders that impair the vascular or neurological structures of the brain (Thobaben, 1999). Sticky plaques and clumps of tangled fibres gradually spread through the brain disrupting the nerve cells. Communications between the nerve cells cease, resulting in their atrophy (Lemonick & Park, 2001). This global impairment is characterized by changes in cognitive functioning, which is progressive, irreversible and degenerative (Fares, 1997).

The cognitive decline caused by this disease, leads to the need for assistance from a carer to ensure ongoing functioning in the community. Caring for a person with dementia can have positive, rewarding aspects but it can also have adverse effects. Higher level of stress, anxiety and depression, general health problems, loneliness and social isolation are reported by caregivers (McGarry & Arthur, 2001).

One of the most distressing problems that a carer may have to deal with is faecal incontinence. Faecal incontinence is defined as: “The involuntary or inappropriate passing of liquid or solid stool and can also include the incontinence of flatus” (Powell & Rigby, 2000 p. 48). A recent study by Kalantar, Howell and Talley (2002), indicates the prevalence of faecal incontinence within Australia to be 11.2%. It is recognized that the incidence of faecal incontinence is under-reported, as is the seeking of help, due largely to it being considered a “taboo” subject (Edwards & Jones, 2001; Kalantar, Howell & Talley, 2002; Prosser & Dobbs, 1997).

In the absence of anatomical or co-morbid disease there are no physiological reasons why dementia should cause incontinence. However, neuro-psychiatric disorders such as dementia have the potential to cause constipation. Wilson (1999) showed that dementia is frequently associated with severe constipation because changes in cognitive function can lead to an inability to recognize the urge to defecate. The cognitive abilities of an individual impact on their ability to appropriately respond to
the physiological stimulus to evacuate either bladder or bowel, to obtain physical assistance from care providers, and to learn other management strategies.

Faecal incontinence has negative implications for both the caregiver and the person with dementia (Cavarra, Prentice & Wellings, 1998). The carer of a faecally incontinent person can be easily overburdened by the physical demands of maintaining cleanliness and preventing complications of skin breakdown and infection. Handling, dealing with and cleaning up faeces is considered dirty work and causes feelings of revulsion and disgust in most people. For the person with dementia, shame, fear and embarrassment associated with faecal incontinence can lead to social isolation, lowered self-confidence and diminished self-esteem (Jenkins, 2000; O’Brien, 1998).

Several studies have highlighted incontinence, aggression, wandering and physical dependency as prime reasons for placing relatives in nursing homes (Armstrong, 2001; Dunkin & Anderson-Hanley, 1998; Gaugler et al., 2000; O’Donnell et al., 1992). The burden and stress involved with faecal incontinence can be the precursor for institutionalization (Jenkins, 2000, Seidel, Mills, Lichtenberg & Dijikers, 1994; Tsuji, Whalen & Finucane, 1995).

Institutionalization has significant implications for the healthcare system. The projected increase in the aged population raises concerns regarding bed need and availability in long-term facilities of the future. The high financial costs associated with providing care within these establishments’ compounds these concerns (Burns, 2000; Gaugler et al., 2000). Further implications of placement include the difficult psychosocial adjustments for the older person and their families (Almberg, Grafstrom & Winblad, 1997a; Clyburn, Stones, Hadjistauropoulos & Tuokko, 2000; Sclan & Kanowski, 2001).

Incontinence is treatable. Treatments for loss of bowel control can include pharmacological and non-pharmacological approaches or even surgery (Cheetham, Kenefick & Kamm, 2001; Kamm, 1998; Norton, 1997). Both, promotion and maintenance of bowel control can often be attained by simple strategies such as fluid intake, dietary fibre, exercise and activity, environment and bowel habit training. These practices may seem unrelated to bowel care; however, have a direct impact on promotion and maintenance of bowel function (Cavarra et al., 1998).

Normal bowel function requires the absorption of water. Ingestion of fluid increases intestinal water content, which produces softer faeces and promotes transit of stool through the colon. Insufficient fluid intake affects the bowel by interfering with the movement of faeces through the colon, thereby precipitating constipation (Anti et al., 1998; Dosh, 2002). In the elderly, untreated constipation can lead to faecal impaction with overflow, a condition often misinterpreted as diarrhoea (Muller-Lissner, 2002). It is not uncommon for symptoms of increased confusion and changes to cognitive functioning to be exhibited in a person with impaction caused by severe constipation (Maestri-Banks & Burns, 1996).

The importance of fibre lies in its ability to promote normal laxation (Marlett, McBurney & Slavin, 2002). Fibre is found only in plant foods. Plant cell walls, which resist breakdown by micro flora, are able to retain water in their cellular
structure. This function enables fibre to have a bulking effect for stools. The resultant bulking stimulates colonic peristalsis, thereby decreasing transit times of stools. The shortened transit times can lead to decreased re-absorption of fluid in the colon with resultant wetter and softer stools. Water absorbency properties of fibre can be of assistance for people with loose or liquid stools. It can increase stool viscosity and further add to stool bulk (Bliss et al., 2001; Cummings, 1984; Ferguson & Harris, 1997; Kaaks & Riboli, 1995; Kilworth, 1995).

Insufficient intake of food as a result of poor dentition can mean that recommended daily dietary fibre quota is reduced (Muller-Lissner, 2002). The recommended quota varies but generally falls in the range of 20 – 35g. Long-term daily fibre intakes of >35g have been found to reduce constipation. In addition, there was no significant association between level of fibre and symptoms of bloating, diarrhoea or upset stomach (McEligot et al., 2002).

Physical activity influences gut motility. Exercise changes the abdominal pressure by relaxing and contracting the abdominal muscles and diaphragm. Additionally, exercise improves the appetite and consumption of food. The combined benefit is the movement of faeces into the rectum (Getliffe & Dolman, 1997). Decreased physical activity and mobility can predispose to constipation (Wilson, 1999).

A clean pleasant smelling, private environment promotes defecation. Interruptions, rushing or poor toilet positioning can contribute to incomplete emptying. If defecation is inhibited, or call to stool ignored or overridden, sensory messages indicating need to defecate may not return for 24-hours. Fluid reabsorption from the large bowel can occur resulting in hardened stools (Cavarra et al., 1998; Getliffe & Dolman, 1997).

External triggers can also help to regain continence (Hutchinson, Leger-Krall & Wilson, 1996). Techniques such as bowel habit training, caregiver alertness to non-verbal cues with subsequent prompted toileting, scheduled toileting and environmental cues can be successful as strategies to regain continence for persons with cognitive deficits (Anders, 2000; Carlson, Fleming, Smith & Evans, 1995; Cavarra et al., 1998; Hutchinson et al., 1996; Schaeffer & Cheskin, 1998).

Carers generally have little or no warning of their impending role and are therefore unlikely to have the necessary knowledge or training. The assistance provided by a carer has the potential to change the level of cognitive functioning and promote the maintenance of independence for a person with dementia. Carer education, then, is seen to be worthwhile (Burns, 2000; Ghatak, 1994).

Support for education and training to help carers cope or reduce burden has been demonstrated by several studies (Chang, 1999; Gallagher-Thompson & DeVries, 1994; Gerdner, Richards Hall & Buckwalter, 1996; Hepburn, Tornatore, Center & Ostwald, 2001; Marriott, Donaldson, Tarrer & Burns, 2000; Richards Hall & Buckwalter, 1987; Teri, 1999).

Nurses are in a prime position to offer practical advice and support to carers of people with dementia about the disease and its management (Armstrong, 2001; Downs & Zarit, 1999). Evidence based practice that minimizes the effects of dementia, along
with further research aimed at documenting the effectiveness of carer education on management of incontinence is required (Brodaty, McGilchrist, Harris & Peters, 1993; Downs & Zarit, 1999; Ouslander, Zarit, Orr & Muira, 1990).

This project is significant because it provides early intervention to enable home carers to promote and maintain faecal continence. As carers receive information and support they will be able to take a pro-active approach to this often hidden aspect of care. It is anticipated that this will result in a reduction in faecal continence problems, enhancement of carer knowledge and skills, minimisation of carer burden, increased dignity for the person with dementia and qualitative improvement in the caring relationship. The educational materials and assessment and intervention techniques developed for this project can be further refined, based on the outcomes of project evaluation. Upon refinement, these materials could be made available to carers, other health professionals and support groups.

3.0 PROJECT IMPLEMENTATION

3.1 Ethical Approval

An application for ethical approval to conduct the project was lodged with the Australian Catholic University Human Research Ethics Committee in December 2000. Ethics approval was granted for the period 15th January 2002 to 31 December 2002. In addition, the Blue Care Human Research Ethics Committee gave ethical approval for the project. There were no problems during the implementation phase that required referral to either Committee.

3.2 Instrument Development

Instruments required for the assessment of each person with dementia and subsequent planning of care, and monitoring of progress were developed by the project team. This development was informed by the expertise within the team, review of relevant literature and consultation with experts in the field of dementia care.

The Faecal Continence Assessment tool (Appendix 2) focused on:

- relevant medical and surgical history, medication and laxative use, level of cognitive function, bowel elimination and toileting patterns, level of mobility and exercise, diet and fluid intake;
- anorectal and abdominal physical examination, if indicated and appropriate;
- audit of environmental factors.

A Bowel Management Program protocol was also established (Appendix 3). This protocol detailed interventions required to correct or more effectively manage actual problems, if they existed, and to prevent the development of potential problems. Interventions focused on correcting, improving and
maintaining aspects such as food and fluid intake, exercise and mobilisation, medication and laxative use, toileting regimes and environmental factors.

A **Summary Sheet** (Appendix 4) was also designed to enable required interventions for each person with dementia to be documented for the home carer and left with them for their ongoing reference.

A daily **Bowel Record Chart** (Appendix 5) for the person with dementia was prepared. With the appropriate permission, this was supplemented by the **Bristol Stool Form Scale** (Appendix 6) to assist carers in maintaining the daily record. Permission to use this scale was provided by the Managing Director, Norgine.

Two instruments were developed for pre and post-testing of home carers. The **Carer Knowledge Questionnaire** (Appendix 7) was developed by the project team specifically to test carers’ knowledge regarding the information that was to be provided in the educational video and accompanying fact sheets, as follows:

- Cognitive and Physiological Change (Questions 1, 2, 3, 4, 5, 6, 7, 8, 9, 11, 22 and 23)
- Fluid intake (Questions 13, 15 and 16)
- Dietary fibre Intake included Questions (Questions 12, 17, 18 and 19).
- Exercise and Activity (Questions 10 and 21)
- Medication (Questions 14 and 20)
- Environment (Question 21)
- Management and Coping (Questions 24 and 25).

Questions 1 to 14 were fixed response items, with the options of agree, unsure or disagree. Questions 15 through to 25 were open-ended questions. Face validity of the tool was assured through reference to relevant research literature and the input of expert nurse continence advisors. Each response was allocated a score so that a total score could be calculated for each participant. The questions were categorized into two sets. Set 1 assessed knowledge on factors contributing to faecal incontinence. Set 2 focused on knowledge of specific strategies to assist with maintaining faecal continence.

The **Experience of Caregiving Questionnaire** (Appendix 8) was adapted by the project team, from the Carer’s Stress and Burden Questionnaire developed by Simon O’Donovan (n.d.). Information supplied by the developer indicated that this tool had a very high level of internal reliability. The developer granted permission for use of some components of the Carer’s Stress and Burden Questionnaire within the project.

The adapted tool comprised 41 questions, each with fixed responses including options of never, rarely, sometimes, frequently and always. Individual questions from the Carer Knowledge Questionnaire can be grouped under
seven major headings. These headings and the questions that were allocated to them are outlined below:

- General Well Being (Question 1, 5 & 11)
- Roles / Relationship (Questions 2, 3, 4, 6, 7, 8 & 9)
- Capacity to Cope (Questions 10, 12, 13, 14, 16, 19, 20, 38, 39 & 40)
- Sense of Loss (Questions 17 & 18)
- Negative Feelings (Questions 15, 21, 22, 23, 24, 25, 26, 27, 28, 29 & 30)
- Positive Feelings (Questions 31, 32, 33, 34, 35, 36 & 37)
- Overall Perception of Caregiving Situation (Question 41).

### 3.3 Preparation of Educational Resources

The project team scripted a sixteen-minute videotape to be used in carer education. Aspects for emphasis within the videotape were those interventions considered by the team to have potential for facilitating and maintaining faecal continence, namely: fluid intake; dietary fibre; exercise and activity; medication use; environment; and bowel habit training. The production company, Media Odyssey, was engaged to produce the videotape entitled, *A practical approach to maintaining bowel control in people with dementia* (Appendix 9). To provide a quality tape within the allocated budget, volunteer actors were sought. Production of this video was enhanced by the untapped natural acting skills, enthusiasm and willingness to be of help to others, which was demonstrated by the volunteer actors. Acknowledgements to these volunteers can also be found in the credits of the video. A fact sheet for each of these interventions was also produced. The fact sheets (Appendix 10) closely followed the organisation of the videotape and reinforced the information provided.

### 3.4 Recruitment

Eligible project participants were people with dementia being cared for at home and their home carer. No age or gender specificity was required. Participants and their home carers were required to speak English and reside in the Brisbane or near metropolitan area. It was expected that the carer would be in reasonable health and able to carry out the role of caregiver. Where there was more than one carer, the primary carer was identified for participation in the project.

The target number of 50 participants and their carers was reached. Recruitment was more difficult than anticipated and insufficient response was received using the recruitment avenues outlined in the project proposal. Various groups were approached directly to assist with recruitment of participants. These included major domiciliary nursing services, day respite
centres, community health centres, major support groups, in home respite providers, Community and Aged Care package providers and local general practitioners. Staff from these services distributed flyers to eligible persons who were invited to contact the Project Officer for further information. Flyers were also posted at local shopping centre notice boards. The Project Officer individually responded to each inquiry by potential participants and provided them with information regarding the project.

3.5 Pre-testing of Carers

The Experience of Caregiving Questionnaire was mailed to participants for them to complete prior to the first visit. On the first home visit, this questionnaire was returned to the Registered Nurse. If this questionnaire had not been completed it was attended at the first visit prior to any educational intervention. The Carer Knowledge Questionnaire was administered at the first visit and completed in the presence of the Project Officer. Alternatively, participants were given the option of having the Project Officer record their responses. No external assistance was received from any other persons.

3.6 Carer Education

Prior to implementation of the Bowel Management Program each home carer received general education regarding the establishment and maintenance of faecal continence. The educational videotape and fact sheets specifically produced for use in this project were left with the home carer for their perusal.

3.7 Assessment, Planning of Interventions and Ongoing Monitoring

Comprehensive faecal continence assessment of all participants, using the Faecal Continence Assessment tool was completed by May, 2002. Assessments were performed by either the Project Officer or members of the project team in the participant’s own home. No problems or refusals were encountered. Assessment data were used to determine the presence of actual and / or potential problems in achieving and maintaining faecal continence. The Bowel Management Program protocol was then used to formulate individualised plans of care to manage the identified problems for the person with dementia. Proposed interventions were documented on the Summary Sheet and explained to the home carer for their implementation. Each home carer was also instructed regarding the completion of the daily Bowel Record Chart using the Bristol Stool Form Scale.

The Project Officer monitored each home carer and person with dementia regularly. This took the form of a home visit at one, two and three months from entry to the project. Contact details for the Project Officer were also provided. At the monitoring visits evaluations were made regarding the efficacy and comprehensiveness of interventions. Where indicated, alterations were made to the Bowel Management Plan and additional education was provided to the home carer.
3.8 Post-testing of Carers
On the last home visit each carer again completed the Carer Knowledge Questionnaire and the Experience of Caregiving Questionnaire.

3.9 Discharge from the Project
On discharge from the project each home carer was provided with a summary of the current faecal continence status of the person in their care and recommendations for ongoing maintenance and promotion of bowel control.

3.10 Unanticipated Difficulties Encountered
Some degree of difficulty was encountered when trying to recruit participants through dementia support groups. Managers of these groups denied access, stating that carers coming to the support group have very limited time away from their role and it would not be suitable to advise or encourage their participation in such a project during this respite time. It was further stated that these groups could only be addressed on invitation. It was also emphasized that these people were already the target of a lot of research.

An unanticipated outcome of comprehensive assessment was the discovery of many unmet care and resource needs. There was a lack of knowledge of services available to assist with the caregiving role including:

- types of regular and emergency support services available and ways to access them;
- inaccurate / incomplete information given by some service providers about eligibility for additional help;
- inactivity of service providers in advocating for access to respite services;
- long delay time between referral to and contact to from support services.

Many carers reported that their General Practitioner had advised them, that faecal incontinence was an expected and normal part of dementia. Some carers, following consultation with the general practitioner, were prescribed incontinence pads as the first and only line of treatment. On a number of occasions Agarol had been recommended for use long-term to assist with constipation Agarol is not recommended for long-term use in the elderly due to the related risk of aspiration. (Aschenbrenner, Cleveland, and Venable, 2002). Safer aperients and options had not been explored.

It was found that a high number of participants who were incontinent were using pads unsuitable for their situation. Many carers were unaware of the range of aids available or how to use them effectively. Often the pads worn did not promote or maximize independence for the person with dementia.
Sometimes daytime pads used were too bulky and uncomfortable for the wearer, or were difficult for the wearer to use independently, thereby causing an increase in dependence on the carer. In other instances the pads used were not effective in containing faecal incontinence episodes, leading to increased carer workload and client discomfort. Often too many pads were being used in a day, impacting on cost effectiveness. A larger capacity pad would have been more suitable and less of a financial burden. Some participants with long-term bladder or bowel problems were not even aware of, let alone affiliated with relevant schemes that assist with supply of continence aids such as the Medical Aids Subsidy Scheme (MASS) (Queensland) or Department of Veterans’ Affairs (DVA).
4.0 RESULTS

A total of fifty carers and persons suffering from dementia being cared for at home were recruited into the study. Within the short time between giving written consent and the commencement of the project three pairs withdrew because one person with dementia was hospitalised and the other two were placed in nursing homes. Forty-seven pairs entered the study. Seven pairs withdrew from the project prior to its completion. One person with dementia died and the remaining six were either hospitalised awaiting placement or placed in a nursing home.

The following demographic data separately describes characteristics of the original forty-seven persons with dementia and their home carers. Data analysis was undertaken using the Statistical Package for Social Sciences (SPSS) release 10 (SPSS Inc, 2001).

4.1 Persons with Dementia

Of the persons with dementia 11 (23.4%) were male and 36 (76.6%) were female. Ages ranged from 56 to 96 years, with a mean age of 80.2 years and a median of 81 years. Figure 4.1 shows the age distribution.

![Age distribution of persons with dementia](image)

Figure 4.1 Age distribution of persons with dementia
The Mini Mental State Examination (MMSE) is a tool used to measure cognitive function. It includes an 11 question measure assessing responses in areas of orientation, registration, attention, recall, calculation and language (Kurlowicz & Wallace, 2002). The maximum score that can be obtained is 30, with a score of 24 or lower indicative of cognitive impairment (Pritchard, 1999). The MMSE scores of participants ranged from 0 to 26, with a mean of 12.50 and a median of 12.50. Score distribution is illustrated in Figure 4.2.

![MMSE Score Distribution](image)

Figure 4.2 MMSE score distribution of persons with dementia

There was a high level of co-morbidity amongst the persons with dementia. The most commonly reported conditions affected the cardiovascular system and were experienced by 39%. The types of conditions identified are those generally found within the older age group (Fig 4.3).

![Co-morbidities](image)

Figure 4.3 Co-morbidities of persons with dementia
4.2 Home Carers
Of the home carers who participated in the study, 20 (42.6%) were male and 27 (57.4%) were female. Ages ranged from 22 to 87 years, with a mean age of 64.6 years and a median of 68 years. Figure 4.4 shows the age distribution.

![Age Distribution of Home Carers](image)

Figure 4.4 Age distribution of home carers

Home carers bore various relationships to the persons with dementia, as outlined in Table 4.1.

<table>
<thead>
<tr>
<th>RELATIONSHIP</th>
<th>FREQUENCY</th>
<th>PERCENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse</td>
<td>22</td>
<td>46.8</td>
</tr>
<tr>
<td>Daughter</td>
<td>17</td>
<td>36.2</td>
</tr>
<tr>
<td>Son</td>
<td>4</td>
<td>8.5</td>
</tr>
<tr>
<td>Friend</td>
<td>2</td>
<td>4.3</td>
</tr>
<tr>
<td>Daughter in law</td>
<td>1</td>
<td>2.1</td>
</tr>
<tr>
<td>Sister</td>
<td>1</td>
<td>2.1</td>
</tr>
</tbody>
</table>

Table 4.1 Relationship of home carer to person with dementia

Forty-five of the home carers had the person with dementia living with them on a full time basis. The other two carers lived elsewhere but were in very frequent contact with the person with dementia. There were varying levels of family support available to the home carer, with only 11 (23.4%) indicating moderate or greater availability. Other supports available to home carers included in home respite (61.7%) and attendance by the person with dementia at day respite (53.2%). Day respite attendances ranged from one to five days per week with the majority being one to two days.
Most (87.2%) of the home carers were not employed outside the home. Two home carers were employed full-time, two part-time and two were students. The majority of carers had no health factors that were likely to interfere with their role as carer; however, 17 (36.2%) had slight to moderate physical or medical limitations.

### 4.3 Continence Status Pre Intervention

Faecal continence status of the person with dementia was recorded as faecally continent, faecally continent with assistance, faecal smearing or faecally incontinent. Faecally continent status included those persons who were independently continent of faeces. Participants who remained continent, as a result of either prompted or scheduled toileting (with or without physical assistance) were assessed as being faecally continent with assistance. Faecal smearing included participants who are continent, but had episodes of smearing on underwear. There are various definitions of faecal incontinence in existence (Kalantar et al., 2002). For the purpose of this project the definition of faecal incontinence that was used was ‘the passing of solid, pasty, or liquid stool in an undesired place, at a frequency of >2 episodes a month’ (Kalantar et al., 2002). Isolated episodes of faecal incontinence related to acute illnesses were excluded from this definition.

Faecal continence status of the persons being cared for prior to carer education and implementation of specific intervention is illustrated in Figure 4.5. Fourteen (35%) of persons with dementia were independently faecally continent, 3 (7.5%) were faecally continent with assistance, 10 (25%) were faecally continent but had faecal smearing and 13 (32.5%) were faecally incontinent.

![Figure 4.5 Faecal continence status pre intervention](image-url)
4.4 Bowel Management Problems
As a result of the extensive assessment of each person with dementia, using the Faecal Continence Assessment Tool (Appendix 2), a broad range of problems that could contribute to difficulty in improving and maintaining faecal continence were identified. These have been categorised into six major contributing factors and are detailed in Table 4.2.

<table>
<thead>
<tr>
<th>MAJOR CONTRIBUTING FACTORS</th>
<th>FREQUENCY OF OCCURRENCE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive and physiological changes</td>
<td>58</td>
</tr>
<tr>
<td>Inadequate fluid intake</td>
<td>17</td>
</tr>
<tr>
<td>Inadequate dietary fibre intake</td>
<td>26</td>
</tr>
<tr>
<td>Inadequate exercise and activity</td>
<td>18</td>
</tr>
<tr>
<td>Medications</td>
<td>3</td>
</tr>
<tr>
<td>Inappropriate environment</td>
<td>11</td>
</tr>
</tbody>
</table>

Table 4.2 Major contributing factors

4.5 Planned Interventions
In relation to cognitive and physiological changes, prescribed interventions were focused on bowel habit training. Where appropriate, optimal amounts and types of fluids and dietary fibre were recommended. When physiologically possible, increased levels of exercise and activity were promoted. Medication problems were addressed in liaison with the relevant General Practitioner, with two people ceasing long-term use of laxatives, three commencing laxative use and one commencing an anti-diarrhoeal agent. Environmental modifications were facilitated and the use of appropriate clothing and toileting aids was encouraged.

4.6 Carer Use of Educational Resources
Home carers were left with their own copy of the educational video and a set of fact sheets. Their usage pattern indicated that, by the end of the 4th week of participation, 17 home carers (42.5%) had accessed all educational materials. A further 9 (22.5%) had done so by the end of the 8th week and 7 (17.5%) by the end of week twelve.

Of the remaining 7, 2 home carers accessed the fact sheets only, 1 accessed the video only and 4 did not access any of the educational resources.

4.7 Experience of Caregiving
Box plot representations have been utilized throughout this report in relevant sections. A box plot helps to visualize the median, interquartile range, and the smallest and largest values of a specified variable. The lower boundary of the box represents the 25th percentile. The upper boundary represents the 75th
percentile. The vertical length of the box illustrates the interquartile range (i.e.; 50% of all cases), while the line inside the box represents the median. The lines above and below this box represent the largest and smallest values within 1.5 box lengths. Any cases with values between 1.5 and 3 box lengths from the upper or lower edge of the box are called outliers and are labelled with an (0). The width of a box does not represent anything; it is the vertical scale that values are plotted against (Norusis, 1998).

T test measures have been used where applicable throughout this report. A t test is a parametric statistical test used for comparing differences between two means. It tests the null hypothesis that the difference in mean between two related variables is 0, and questions whether the mean scores on some measures are different from what would be expected by chance (Beanland, Schneider, LoBiondo-Wood & Haber, 2000; Norusis, 1998). A confidence interval of 95% was specified for all t tests undertaken in this project. A probability (p) of 0.05 or less is statistically significant and indicative of a degree of confidence in the measure (Polit & Hungler, 1995).

Pre-testing of home carers’ experience of caregiving resulted in a total score for each participant (maximum 250); with a higher score indicative of less carer stress and burden. Totals of individual participant pre and post-test scores are represented in a box plot illustration in Figure 4.6.

Pre-test scores ranged from 80 to 170, with a mean score of 136.15 (SD = 19.47), and a median of 140. Post-test scores ranged from 82 to 165, with a mean score of 137.85 (SD= 17.85), and a median of 138. There was no statistical significance between pre and post-test for the home carers experience of caregiving as assessed by a repeated measures t test (t (39) = .790, p=.434).

![Box plot illustration](image)

**Figure 4.6** Individual scores pre and post-test for Experience of Caregiving Questionnaire
Scores were also computed against grouped responses relating to:

- roles and relationships;
- capacity to cope;
- negative feelings;
- positive feelings;
- general well being;
- sense of loss;
- overall perception of caregiving.

Four of these groups were tested with repeated measures t test. The roles and relationships group consisted of 7 items, and had a maximum score of 35. There was no statistically significant difference between the pre-test (mean = 18.70) and the post-test (mean = 19.23) as assessed by a repeated measures t test ($t_{(39)} = .894$, $p = .377$) (Figure 4.7).

![Figure 4.7](image1.png)

Figure 4.7      Grouped responses for pre and post-test scores, roles and relationships

The capacity to cope group consisted of 10 items and had a maximum score of 50. There was no statistically significant difference in this group between the pre-test (mean = 35.30) and the post-test (mean = 35.48) as assessed by a repeated measures t test ($t_{(39)} = .237$, $p = .814$) (Figure 4.8).

![Figure 4.8](image2.png)

Figure 4.8      Grouped responses for pre and post-test scores, capacity to cope
The group of negative feelings included 11 items and had a maximum score of 55. There was no statistically significant difference between the pre-test (mean = 39.15) and the post-test (mean = 39.73) as assessed by a repeated measures t test \((t_{39} = .817, p=.419)\) (Figure 4.9).

![Figure 4.9](image)

**Figure 4.9** Grouped responses for pre and post-test scores, negative feelings

The group of positive feelings associated with caregiving included 7 items with a maximum score of 35. Repeated measures t test between pre-test (mean = 25.05) and post-test (mean = 25.33) where \(t_{39} = .405, p=.687\) did not indicate any statistically significant difference (Figure 4.10).

![Figure 4.10](image)

**Figure 4.10** Grouped responses for pre and post-test scores, positive feelings

Some of the groups consisted of only 2 or 3 items, and any differences in the individual items of these groups will be represented. Tables of crosstabulation and t test analysis of the individual items between pre and post-test responses will be reported where appropriate throughout the report.

Crosstabulation is used to look at the relationships between two variables that have small numbers of values or categories. A table is produced that contains counts of the number of times combinations of values of two variables occur (Norusis, 1998). The rows are indicative of pre-test results, with the totals of each row located on the far right of the table. The columns denote post-test.
results, with the totals of each column located on the bottom of the table. The margins on the table show changes in response for each of the two variables. The figure located at the bottom right hand corner of the table specifies the number of persons included in the crosstabulation (Norusis, 1998).

The general well being group consisted of 3 items. Table 4.3 shows crosstabulation of pre and post-test responses to Question 1 (Perception of need for a holiday [a long-term break from caring]). Most (n = 23, 57.5%) participants gave the same response pre and post-test, indicating that sometimes they felt they needed a holiday. Nine (22.5%) responses indicated an increase in the need for a holiday, while 8 (20%) showed a reduced need for a holiday. Repeated measures t test for this question indicated there was no statistically significant difference, with t test (t(39) = .350, p=.728).

<table>
<thead>
<tr>
<th>Question 1</th>
<th>Post</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Never</td>
</tr>
<tr>
<td>Pre</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>Count</td>
</tr>
<tr>
<td></td>
<td>% of Total</td>
</tr>
<tr>
<td>Rarely</td>
<td>Count</td>
</tr>
<tr>
<td></td>
<td>% of Total</td>
</tr>
<tr>
<td>Sometimes</td>
<td>Count</td>
</tr>
<tr>
<td></td>
<td>% of Total</td>
</tr>
<tr>
<td>Frequently</td>
<td>Count</td>
</tr>
<tr>
<td></td>
<td>% of Total</td>
</tr>
<tr>
<td>Always</td>
<td>Count</td>
</tr>
<tr>
<td></td>
<td>% of Total</td>
</tr>
<tr>
<td>Total</td>
<td>Count</td>
</tr>
<tr>
<td></td>
<td>% of Total</td>
</tr>
</tbody>
</table>

Table 4.3       Perception of need for a holiday (a long-term break from caring)

Question 5 assessed if sleep was disrupted as a result of the caring role. Repeated measures t test indicated no significant change between pre and post-testing, with a t test of (t(37) = .154, p=.878) (Table 4.4).
Table 4.4  Sleep disruption from caring role

Pre and post-test comparison for Question 11, (physical health changes as result of care giving) indicated there was no statistically significant change in this area as assessed by repeated measures t test (t (38) = 1.000, p= .324) (Table 4.5).

Table 4.5  Physical health changes as result of caregiving
The two items in the sense of loss group included Questions 17 and 18. Crosstabulation of Question 17 (distress for carer associated with changes to former self of dependant) can be viewed in Table 4.6. Repeated measures t test for this question indicated there was no statistically significant difference, with t test ($t(39) = 1.883, p=.067$).

<table>
<thead>
<tr>
<th>Question 17</th>
<th>Post</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Frequently</th>
<th>Always</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rarely</td>
<td>Count</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>% of Total</td>
<td>2.5%</td>
<td>2.5%</td>
<td></td>
<td></td>
<td></td>
<td>5.0%</td>
</tr>
<tr>
<td>Sometimes</td>
<td>Count</td>
<td>1</td>
<td>2</td>
<td>6</td>
<td>4</td>
<td></td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>% of Total</td>
<td>2.5%</td>
<td>5.0%</td>
<td>15.0%</td>
<td>10.0%</td>
<td></td>
<td>32.5%</td>
</tr>
<tr>
<td>Frequently</td>
<td>Count</td>
<td>6</td>
<td>4</td>
<td>2</td>
<td>12</td>
<td></td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>% of Total</td>
<td></td>
<td>15.0%</td>
<td>10.0%</td>
<td>5.0%</td>
<td></td>
<td>30.0%</td>
</tr>
<tr>
<td>Always</td>
<td>Count</td>
<td>2</td>
<td>3</td>
<td>8</td>
<td>13</td>
<td></td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>% of Total</td>
<td></td>
<td>5.0%</td>
<td>7.5%</td>
<td>20.0%</td>
<td></td>
<td>32.5%</td>
</tr>
<tr>
<td>Total</td>
<td>Count</td>
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<td>3</td>
<td>15</td>
<td>11</td>
<td>10</td>
<td>40</td>
</tr>
<tr>
<td></td>
<td>% of Total</td>
<td>2.5%</td>
<td>7.5%</td>
<td>37.5%</td>
<td>27.5%</td>
<td>25.0%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Table 4.6 Distress for carer associated with changes to former self of dependant

Similarly, for Question 18 (Table 4.7) there was no statistically significant change when analysed using repeated measures t test. This question assessed feelings of grief and loss associated with the caring role. The result of t test is ($t(37) = .291, p=.772$).
Table 4.7 Feelings of grief and loss associated with caring role

The final group comprised Question 41 and assessed overall perception of the caregiving situation. A crosstabulation of changes is represented in Table 4.8. Repeated measures t test indicated no statistically significant change (t \(_{(38)} = 1.071, p = .291\)).
### Table 4.8  Overall perception of the caregiving situation.

<table>
<thead>
<tr>
<th>Question 41</th>
<th>Pre</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Count</td>
<td></td>
<td></td>
</tr>
<tr>
<td>% of Total</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coping well No stress</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>% of Total</td>
<td>2.6%</td>
<td>2.6%</td>
</tr>
<tr>
<td>Coping Fairly well, Low Stress</td>
<td>2</td>
<td>22</td>
</tr>
<tr>
<td>% of Total</td>
<td>5.1%</td>
<td>56.4%</td>
</tr>
<tr>
<td>Just about Coping - Much stress</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>% of Total</td>
<td>10.3%</td>
<td>10.3%</td>
</tr>
<tr>
<td>Difficulty coping - Much Stress</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>% of Total</td>
<td>2.6%</td>
<td>2.6%</td>
</tr>
<tr>
<td>Almost not coping - extreme stress</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>% of Total</td>
<td>2.6%</td>
<td>2.6%</td>
</tr>
<tr>
<td>Total</td>
<td>3</td>
<td>27</td>
</tr>
<tr>
<td>% of Total</td>
<td>7.7%</td>
<td>69.2%</td>
</tr>
<tr>
<td></td>
<td>8</td>
<td></td>
</tr>
<tr>
<td></td>
<td>20.5%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2.6%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>100.0%</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Post</th>
<th>Coping well No stress</th>
<th>Coping Fairly well, Low Stress</th>
<th>Just about Coping - Much stress</th>
<th>Almost not coping - extreme stress</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Count</td>
<td>1</td>
<td>22</td>
<td>4</td>
<td>1</td>
<td>39</td>
</tr>
<tr>
<td>% of Total</td>
<td>2.6%</td>
<td>56.4%</td>
<td>10.3%</td>
<td>2.6%</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

4.8  Carer Knowledge

Carer knowledge was measured by scoring responses for each of two sets of questions. The first set (Set 1) included questions 1 to 15 and question 18 and covered factors contributing to faecal continence and incontinence. Correct responses were allocated a score of 1. The second set (Set 2) included Questions 16, 17 and 19 through to 25 and required more in-depth responses from participants. These questions assessed knowledge on specific strategies to assist with maintaining faecal continence and awareness of factors other than dementia that can impact on bowels. The responses from each participant were scored against the possible options. As the individual questions in Set 2 each had differing possible scores, these scores were standardized into quartiles, with 0=25% indicating very low knowledge, 26-50% low knowledge, 51-75% moderate knowledge and 76-100% high knowledge.
The total score of each individual participant was calculated by adding the total number of correct scores for each question. The maximum score possible was 55. The pre-test scores of each participant ranged from 12 to 33, with a mean score of 22.55 and a median of 22. Scores obtained post-test indicated that total scores ranged from 17 to 44 (median = 32.5). Figure 4.11, is a box plot illustration of this score distribution.

![Box plot illustrating score distribution](image)

Figure 4.11  Total scores for Carer Knowledge Questionnaire pre and post-test

There was a statistically significant difference in the total scores of individuals between the pre-test (mean = 22.55) and the post-test (mean = 31.98) when assessed by repeated measures t test (t (39) = 11.634, p<.001).

Table 4.9 displays pre and post-test responses for Set 1, which related to knowledge about factors contributing to faecal continence and incontinence. Responses for Set 1 have been tabled as correct, did not know, or incorrect; and arranged in descending order according to percentage of correct responses from pre-test scores.
Table 4.9 Pre and post-test responses, Set 1

<table>
<thead>
<tr>
<th>Question</th>
<th>Pre – test</th>
<th>Correct</th>
<th>Don’t Know</th>
<th>Incorrect</th>
<th>Post-test</th>
<th>Correct</th>
<th>Don’t Know</th>
<th>Incorrect</th>
</tr>
</thead>
<tbody>
<tr>
<td>12</td>
<td>97.5</td>
<td>2.5</td>
<td>0</td>
<td>100</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>10</td>
<td>87.5</td>
<td>12.5</td>
<td>0</td>
<td>95</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>3</td>
<td>87.2</td>
<td>10.3</td>
<td>2.6</td>
<td>97.4</td>
<td>2.6</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>1</td>
<td>85</td>
<td>15</td>
<td>0</td>
<td>95</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>4</td>
<td>82.1</td>
<td>12.8</td>
<td>5.1</td>
<td>82.1</td>
<td>10.3</td>
<td>7.7</td>
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<td>7</td>
<td>77.5</td>
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<td>80</td>
<td>15</td>
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<td>0</td>
</tr>
<tr>
<td>2</td>
<td>77.5</td>
<td>15</td>
<td>7.5</td>
<td>82.5</td>
<td>17.5</td>
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<td>6</td>
<td>75</td>
<td>20</td>
<td>5</td>
<td>87.5</td>
<td>10</td>
<td>2.5</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>15</td>
<td>65</td>
<td>30</td>
<td>5</td>
<td>75</td>
<td>7.5</td>
<td>17.5</td>
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<td>0</td>
</tr>
<tr>
<td>5</td>
<td>62.5</td>
<td>20</td>
<td>17.5</td>
<td>75</td>
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<td>10</td>
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<td>0</td>
</tr>
<tr>
<td>14</td>
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<td>43.6</td>
<td>0</td>
<td>87.2</td>
<td>12.8</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>13</td>
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<td>33.3</td>
<td>17.9</td>
<td>59</td>
<td>20.5</td>
<td>20.5</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>8</td>
<td>40</td>
<td>57.5</td>
<td>2.5</td>
<td>75</td>
<td>22.5</td>
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<td>0</td>
</tr>
<tr>
<td>11</td>
<td>30</td>
<td>70</td>
<td>0</td>
<td>60</td>
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<td>55</td>
<td>42.5</td>
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</tr>
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<td>5</td>
<td>72.5</td>
<td>22.5</td>
<td>55</td>
<td>12.5</td>
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</tbody>
</table>

On pre-test, 8 of the 16 questions scored correct responses for at least 70% of the group. Interestingly for Question 12, 97.5% of participants correctly recognized the importance of fibre in the diet. Responses to Question 18, 9, 11, 14, 8, and 13 highlighted areas of least knowledge. For each of these questions, at least 42% of the group responded with either incorrect, or did not know. This was most evident in Question 18, where 72.5% of the group did not know the recommended daily amount of dietary fibre and 22.5% responded incorrectly. In Question 9, 75% of the group did not know that poor fitting dentures or poor condition of teeth could impact on bowel function and 7.5% answered incorrectly. In Question 11, 70% did not know if increased confusion could be associated with constipation. For Question 14, 43.6% did not know that pear juice contains sorbitol and can help keep bowels regular. Fifty seven and a half percent of participants responded with did not know, and 2.5% of participants responded incorrectly to Question 8, assessing knowledge on whether constipation can lead to loss of bowel control. Question 13, ascertaining if tea and coffee affect water loss had a 33.3% response of did not know, and 17.9% with an incorrect response. Sixty five percent of participants were correct in response to the amount of fluid required each day, in contrast to a low 9.1% who responded correctly to the amount of dietary fibre required each day.

Post-test, all but one question demonstrated an increase in the number of correct responses.

The areas of most significant change relate to Questions 18, 9, 11, 8 and 14. Question 18, assessed knowledge on the amount of dietary fibre required daily. Post-test the number of correct responses had increased by 50%. This
represents a positive increase from pre-testing results, where the majority of participants did not know the correct amount of fibre required, compared to the post-test result of only 12.5% indicating they did not know. Comparison between pre and post-test results for Question 9 (Poor fitting dentures or poor condition of teeth can impact on bowel function) revealed an increase in correct responses of 37.5%. The assessment of participant knowledge for Question 11 (Increased confusion in persons with dementia may be associated with constipation) had an increase in correct response rate of 30%. Question 8, assessed knowledge on whether constipation can lead to loss of bowel control, and results at post-test indicated an increase in correct response by 35%. Responses for Question 14 (Pear juice contains a natural laxative called sorbitol and can help keep bowels regular) had an increase of 30.8% in correct response rate.

An illustration of pre and post-test responses for Set 1 questions can be found in Figure 4.12 and 4.13 respectively.

![Figure 4.12](image)

**Figure 4.12** Pre-test responses (Question 1-15, & 18) to Carer Knowledge Questionnaire
A comparison of pre and post-test results for Set 2 indicates an increase in knowledge, on specific strategies to assist with maintaining faecal continence and awareness of factors other than dementia that can impact on optimal bowel function. Table 4.10 displays pre and post-test results for the Set 2 questions.

<table>
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<tr>
<th>Question</th>
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<th>Post-test</th>
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</thead>
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<td>26-50% Low</td>
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<td>5</td>
</tr>
<tr>
<td>25</td>
<td>70</td>
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</table>

Table 4.10 Pre and post-test responses (Question 16, 17 & 19 - 25) to Carer Knowledge Questionnaire

Comparison of changes between pre and post-testing for Question 16 (Figure 4.14) indicated an increase in knowledge of things that could be tried to increase fluid intake for persons with dementia. Seventy percent of the group had score ranges indicative of low or moderate knowledge level, with no participants scoring over 76% in the high knowledge level.
Within Question 17 (Figure 4.15), 37.5% of the group had increased their understanding of how dietary fibre helps the bowel function. No participants scored in the high knowledge level.

Knowledge on foods that contained fibre (Question 19, Figure 4.16) increased, with most (60%) now scoring in the low category and 30% attaining scores indicative of a moderate knowledge level.
Post-test scores for Question 20 (Figure 4.17), indicated that 82.5% of participants now had scores above 76%. This is an increase in knowledge of 57.5% when compared to the pre-test result.

![Figure 4.17](attachment:image.png)

**Figure 4.17** Effect of medication on bowel function

In Question 21 (Figure 4.18), no participants scored above 50% of the maximum possible score at either pre or post-testing. Most persons (92.5%) continued to score in the very low category for the length of the project, with only 7.5% moving to the category of low knowledge.

![Figure 4.18](attachment:image.png)

**Figure 4.18** Things to promote independence in toileting

Awareness of the non-verbal signs of the need to toilet (Question 22, Figure 4.19) increased on review at post-test. Most (67.5%) continued to remain in the very low knowledge category; however, 30% had now moved into the low category and 2.5% scored moderately.

![Figure 4.19](attachment:image.png)

**Figure 4.19** Non-verbal signs indicative of need to toilet
Understanding of the causes of loss of bowel control (Question 23, Figure 4.20) increased, with most (67.5%) on post-testing attaining scores in the low knowledge category and 7.5% moving into the moderate category.

![Figure 4.20 Causes of loss of bowel control](image)

On pre-testing 92.5% of participants had a very low understanding of how to manage loss of bowel control (Question 24, Figure 4.21). Post-test scores indicated understanding had increased with 55% now obtaining a low knowledge category score, 2.5% a moderate category score and 2.5% now scoring in the high knowledge category.

![Figure 4.21 Management of loss of bowel control](image)

Comparison of scores between pre and post-testing for Question 25 (Figure 4.22) revealed that knowledge on how to seek help for bowel problems had increased. Scores were distributed across all levels on post-testing, with most (45%) now scoring in the low knowledge category, 15% scoring in the moderate knowledge category and 2.5% scoring in the high category.
In addition to analysing the above data relating to the Total Score, Set 1 questions and Set 2 questions, each question was subjected to further analysis as part of one of the following seven major groups:

- Cognitive and physiological change;
- Fluid intake;
- Dietary fibre intake;
- Exercise and activity;
- Medication;
- Environment;
- Management and coping.

The cognitive and physiological changes group consisted of 12 items, with a maximum possible score of 18. There was a statistically significant increase in the knowledge of cognitive and physiological changes between the pre-test (mean = 8.43) and the post-test (mean = 11.05) as assessed by a repeated measures t test ($t_{(39)} = 5.628$, $p<.001$). An illustration of these changes can be viewed in Figure 4.23.

The fluid intake group consisted of 3 items, with a maximum possible score of 8. There was a statistically significant increase in the knowledge of fluid intake between the pre-test (mean = 3.53) and the post-test (mean = 4.97) as assessed by a repeated measures t test ($t_{(39)} = 4.709$, $p<.001$). The box plots in Figure 4.24 portray the pre and post-test changes for this heading.
The dietary fibre intake group consisted of 4 items, with a maximum possible score of 13. This group (Figure 4.25) when analysed also indicated a significant increase in knowledge between pre-test (mean = 3.90) and post-test (mean = 6.78), with a repeated measures t test of \( t_{(39)} = 10.618, p<.001 \).

The remaining four groups consisted of only 2 or 3 items, and any differences in the individual items of these groups will be represented. Tables of crosstabulation and t test analysis of the individual items between pre and post-test responses will be reported. A confidence interval of 95% was specified for measurement of the individual items.

The exercise and activity group contained 2 items namely Question 10 and Question 21. Crosstabulation on pre and post-test responses for Question 10, indicated that pre-test 87.5% had correct responses and 12.5% were unsure if exercise helped to keep bowels regular. Post-test responses improved with 7.9% moving from unsure to correct, with the total of correct responses increasing to 95%. The remaining 5% responded with unsure. Representation of this can be seen in Table 4.11.
### Table 4.11  Exercise helps keep bowels regular

Analysis using repeated measures $t$ test identified that there was no significant change in knowledge for Question 10, with a $t$ test result of ($t_{(39)} = 1.778$, $p = .083$).

Comparisons of responses pre and post-testing of things that can promote independence in toileting (Question 21) can be seen in Table 4.12. The maximum attainable number of responses for this question was 25. No participant scored above 9 correct answers; however, a trend of increasing scores was evident indicating an increase in knowledge base. Pre-test, 24 persons (60%) were unable to respond with a correct answer, 10 persons (25%) got a score of 1, while the remaining 6 persons (15%) score ranged from 2 to 4. Post-testing indicated only 1 person (4.2%) was unable to respond with a correct answer. Scores ranged from 0 to 9, with 72.5% attaining between 3 and 5 correct responses.
### Question 21

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</table>

Table 4.12   Things that promote independence in toileting

There was a statistically significant increase in the knowledge of factors that increase independence with toileting between the pre-test (mean = .70) and the post-test (mean = 3.90) as assessed by a repeated measures t test (t<sub>39</sub> = 11.24, p<.001).

The group of medication includes Question 14 and 20. Crosstabulation of pre and post-test responses for Question 14 indicate that at pre-test, 22 persons (56.4%) knew that pear juice contains sorbitol and that this can assist with promoting bowel regularity. The remaining participants were unsure (43.6%) if this was accurate. Post-testing indicated an increase in correct responses with 34 persons (87.2%) agreeing, and 5 persons (12.8%) indicating they were unsure. An illustration of this change can be viewed in Table 4.13.
Table 4.13  Pear juice contains sorbitol and can help keep bowels regular

<table>
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<th>Total</th>
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<tr>
<td>Agree</td>
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<td>% of Total</td>
<td>87.2%</td>
<td>12.8%</td>
</tr>
</tbody>
</table>

A repeated measures t test result of \( t_{38} = 3.689, p=0.001 \) for Question 14, indicates a significant increase in knowledge between the pre-test (mean = 1.44) and the post-test (mean = 1.13).

Comparisons of responses pre and post-testing on how medication can impact on bowel function (Question 20) can be seen in Table 4.14. The maximum number of correct responses for this question was 2. Pre-test 16 persons (40%) were unable to respond with a correct answer, while the remaining persons scored at least a 1 or 2. Post-test responses changed positively with the figures indicating an increase in knowledge base. Maximum scores of 2 were attained by most of the group (82.5%).
Table 4.14  Effect of medication on bowel function

There was a statistically significant increase in the knowledge of the effects of medication on bowel function between the pre-test (mean = .85) and the post-test (mean = 1.80) as assessed by a repeated measures t test ($t_{(39)} = 7.675$, $p<.001$).

The group of environment contained only one item. This item is Question 21. As this question is also included in the group of exercise and activity, changes for this question have previously been outlined.

Management and coping was the final group and included 2 items (Question 24 and 25), each with a maximum possible score of 8 and 4 respectively. Crosstabulation between pre and post-test responses on how a carer can manage episodes of loss of bowel control (Question 24) also showed a positive change (see Table 4.15). Pre-test 12 persons (30%) had no correct responses, while most (62.5%) had a score of either 1 or 2. Post-test all persons responded with at least 1 correct answer. Scores ranged from 1 to 7; however, a high percentage of persons (53%) now scored between 3 or 4 correct responses.
There was a statistically significant increase in knowledge for this question between pre-test (mean = 1.05) and the post-test (mean = 2.70) as assessed by a repeated measures t test ($t_{(39)} = 8.337$, $p < .001$).

Question 25 tested knowledge on sources of help for bowel problems. Pre-test 25% of persons did not provide a correct response. Other scores ranged from 1 to 3, with 45% scoring at least 1 correct answer. Post-test a score of 0 was given to 1 person; all other participants were able to get scores ranging from 1 to the maximum of 4, with most (60%) having scores of 2 or 3. Table 4.16 outlines score changes.
### Table 4.16  Seeking help for bowel problems

This question had a statistically significant increase in knowledge between pre-test (mean = 1.08) and post-test (mean = 1.80) as assessed by a repeated measures t test ($t_{(39)} = 5.619$, p<.001).

#### 4.9 Continence Status Post Interventions

Faecal continence status of the persons being cared for pre and post carer education and implementation of specific intervention is illustrated in Figure 4.26. Sixteen (40%) persons with dementia were independently faecally continent post educational intervention. This indicates an increase of 5% when compared to the 35% who were faecally continent prior to educational intervention. The percentage of those who were faecally continent with assistance remained the same, at 7.5%. The faecal smearing frequency decreased over the course of the project, with 6 persons (15%) now having faecal smearing, compared to 10 persons (25%) prior to educational intervention. The number of persons who were faecally incontinent at the end of the project increased by 2, to a total of 15 (37.5%).
Figure 4.26 Faecal continence status pre and post intervention
5.0 DISCUSSION AND RECOMMENDATIONS

The results that were described in the previous section will be interpreted and discussed. Additionally, limitations of the project and recommendations will be identified in each section as appropriate.

5.1 Characteristics of Person with Dementia

Review of Figure 4.1, suggests that the persons with dementia being cared for at home are representative of the expected age group, with most being 75 years or over. The high percentage of females in the group was an unexpected finding. It is difficult to explain this, except that the longevity of females is known to be greater than that of males (Commonwealth Department of Health and Aged Care, 2002).

The MMSE scores of the persons with dementia (Figure 4.2) ranged over a broad spectrum. It is generally accepted that a lower MMSE score equates with greater loss of cognitive function and a correspondingly higher level of care requirements. Cognitive functioning declines over time, and a lower MMSE score is expected as the length of time following diagnosis increases. The MMSE tool has been validated and extensively used in both clinical practice and research. The weakness of this tool lies in its reliance on verbal response and reading and writing. Participants who are hearing and visually impaired or with communication disorders may perform poorly even when cognitively intact. Likewise, people with high intelligence might be able to answer the questions even though they have dementia, while people who have had a poor education may score lower in parts of the screening test associated with their prior educational level rather than with their dementia (Insel & Badger, 2002; Kurlowicz & Wallace, 2002; Pritchard, 1999). Two persons with dementia scored above 24, and 13 persons with dementia scored at 5 or less on the MMSE. These scores may be related to some of the described weaknesses associated with this tool. It is acknowledged that a complete clinical assessment of mental status would gain a more accurate picture of cognitive capacity.

5.2 Characteristics of Home Carers

Consistent with current literature, most (60%) of the carers in this project were 60 years or over, and caring for a person in their own age group (Commonwealth Department of Health and Aged Care, 1998). The 35 to 65 year age range of carers is indicative of the phase of life during which people are most likely to be caring for their parents (Trewin, 2001).

Primary carers were predominantly family members. The primary caring role is most often performed by a partner or daughter of the recipient of care. Review of Table 4.1 provides support for this assertion. Within this project, spouses predominated as the primary carers. It is usual for female spouses to undertake the role of carer. The high percentage of female recipients of care (77%) in this project explains the higher than expected percentage of male
spouses (32.5%) as primary carers. (Commonwealth Department of Health and Aged Care, 1999).

Most carers lived with the person being cared for. It is expected that a high proportion of carers 65 years and over will live with the recipient of care. Primary carers, who care for a parent, have generally been found to live elsewhere; however, in this project most resided with their parents (Trewin, 2001). Consistent with current literature, few of the carers less than 65 years were employed. This could indicate that time spent caring impacts on the capacity to engage in paid employment (Trewin, 2001).

Twenty five percent of the group received moderate or higher levels of support from their immediate family. Most carers in this project were not well supported in their role by their immediate family. This factor can increase the level of carer stress and ability to cope with their caregiving role. Increased longevity, changing family structures and residence patterns, an increasing adult female workforce and unexpressed care support needs are all factors that can influence the level of support received by and provided to primary carers from their immediate family (Grunfeld, McDowell & Danbrook, 1997; McGarry & Arthur, 2001; Shyu, 2000).

5.3 Continence Status Pre Interventions

On entering the project approximately two thirds of the people with dementia were faecally continent. The remaining one third was faecally incontinent. This high proportion of faecally continent persons with dementia being cared for at home is congruent with the literature which identifies faecal incontinence as a precursor for placement (Jenkins, 2000; Seidel et al., 1994; Tsuji et al., 1995).

Ten (25%) persons with dementia had faecal smearing. It was noted that carers considered these people as faecally continent. Furthermore, they did not consider faecal smearing to be problematic, indicating that it was related to urgency or hygiene problems. Revulsion and disgust associated with faecal incontinence (Cavarra et al., 1998; Jenkins, 2000) were not verbalized by these carers. Furthermore, the perceptions of carers in relation to faecal smearing may also impact on their perceived value of strategies to promote and maintain faecal continence. The carers of those people who were faecally incontinent, had first hand experience of the caregiving challenges associated with this condition and the effects it can have.

During the collection of the clinical data, it was noted that many carers of persons with dementia who were faecally continent questioned the relevance of participating in the project. They felt that, as currently there were no problems with faecal incontinence, their participation was probably not suitable. A lack of recognition of the impact that loss of bowel control can have for carers and persons with dementia, may mean awareness of the importance of implementing preventive strategies is not known and therefore not of perceived relevance to their situation. This perception may impact on
knowledge seeking behaviour in relation to promoting and maintaining bowel control. Carers are generally unlikely to have received education or training for their role prior to becoming carers. Instead, there is a tendency to learn the role along the way (Burns, 2000; Ghatak, 1994).

**Recommendation 1**

That education for carers of people with dementia stresses the importance of implementing pro-active strategies for maintaining and improving faecal continence.

**5.4 Bowel Management Problems**

Older age and its accompanying age related changes, cognitive changes associated with dementia, and the co-morbidities of the persons with dementia in this project, most likely contributed to the high number of cognitive and physiological factors impacting on faecal continence that were found at assessment.

A high frequency of inadequate fluid and dietary fibre intake amongst the persons with dementia was evident following assessment. The nature and amount of food and fluid intake by dependents is generally provided by caregivers (Marlett, McBurney & Slavin, 2002; Mentes, 2000). Although awareness of the importance of fibre was found to be very high, there was a very low level of knowledge on the recommended daily intake and sources of dietary fibre. The frequency of inadequate fluid intake identified is supported by the finding of a low knowledge level regarding daily fluid requirements.

In many cases there was also a high frequency of inadequate exercise and activity. This may be directly related to physiological ageing changes, co-morbidities, and the degree of cognitive change associated with dementia. Home carer age and co-morbidities can also influence exercise and activity levels of the dependent.

The environment is important for the promotion of maximum independence and safety. Knowledge of home carers in ways to promote or maximize independence was very low, suggesting a linkage between this and the high frequency of inappropriate environmental factors that could contribute to difficulty in improving and maintaining faecal continence.

**Recommendation 2**

That education for carers of people with dementia includes specific information regarding recommended daily intakes of fluid and dietary fibre, optimal levels of activity and exercise and possible environmental modifications.
5.5 Planned Interventions

All of the interventions that were planned particularly in relation to dietary and fluid intake were straightforward and well within the capabilities of the home carers. Advice regarding modifications to current practices was well received and generally well implemented.

Recommendation 3

That education for carers of people with dementia includes specific strategies to ensure that the person with dementia is able to achieve recommended daily intakes of fluid and dietary fibre.

Attempts to increase levels of exercise and activity were challenging. The impact of co-morbidities, level of cognitive loss, behavioural problems, caregiver health status, supports and level of stress were contributing factors impacting on exercise and activity. Referral to and commencement of a volunteer walking program was an effective intervention to increase exercise, where appropriate.

Recommendation 4

That education for carers of people with dementia includes specific strategies to ensure that the person with dementia is able to achieve and maintain optimal levels of activity and exercise within their limitations and that these strategies address referral to appropriate programs.

When considering environmental modifications, effectiveness of strategies was context dependent. There were no environmental strategies that would be a recommendation for use by all. An individual’s cognitive loss and the impact it had on their toileting process, impacted on strategies that were suitable for their use. For example, way-finding cues were only necessary for those unable to find the toilet. They were not suitable for use in people who already knew the way. Interestingly, some persons with dementia did not tolerate way-finding cues being put up in the home; instead, they removed them. This may relate to their concepts of privacy associated with toileting.

Strategies recommended for identified deficits in the ability to recognize the toilet were; use of a coloured toilet seat, changing of toilet water colour and removal of items mistaken for receptacles. The number of participants in the project with this deficit was few, therefore effectiveness of this type of intervention was difficult to ascertain.

When indicated the promotion of safety and independence was undertaken by referral to appropriate health services and bodies (following discussion and verbal approval from the caregiver). These types of referrals included assessment for hand rails, over-toilet chairs, and sensor lights. Advice
regarding removal of hazards and clearing of pathways was promoted as necessary. Generally this advice was acted on.

**Recommendation 5**

That education for carers of people with dementia includes specific information regarding environmental modification, with emphasis on relevant contextual and individual factors.

It was found that caregivers easily conceptualized the different stool types utilizing the Bristol Stool Form Scale. Use of this enhanced understanding of desired stool types and facilitated mutual terminology between caregivers and the Project Officer.

**Recommendation 6**

That the Bristol Stool Form Scale be used in education for carers of people with dementia to increase knowledge of optimal bowel function.

Use of a footstool to facilitate correct toileting position and effective evacuation was not appropriate for persons with dementia who did not require assistance to toilet. The reason for this was that a footstool posed a high hazard level within the toilet environment (especially for this age group); thereby increasing the likelihood of falls for those who independently toileted. In addition, cognitive deficits may impact on the ability to recognize the intended purpose and use of the footstool.

**Recommendation 7**

That the use of a footstool to facilitate correct toileting position not be recommended for people with dementia who toilet independently.

The implementation of bowel habit training was difficult and often impossible for some carers to undertake. This was due to the inability of the person with dementia to stay seated on the toilet. In these cases, persisting with bowel habit training was stressful for both parties. As a consequence, this was an unsuccessful technique when trying to establish regular timed bowel motions, specifically for those persons with an inability to stay seated on the toilet.

**Recommendation 8**

That bowel habit training not be recommended as a strategy for use in some people with dementia.
It was identified that caregivers expressed a preference for non-pharmacological methods to promote bowel regularity and function. Some of the most successful interventions were:

- Increasing dietary fibre intake through use of bulking agents
- Increasing fluid intake
- Use of pear juice containing the natural laxative, sorbitol (Stumm, Spence Thomas, Coombes, Greenhill & Hay, 2001).

Willingness to promote simple bowel promotion strategies in an effort to decrease reliance on medication was evident. Additionally, understanding of potential side effects and impact of medication on bowel continence increased.

**Recommendation 9**

That education for carers of people with dementia emphasises the use of non-pharmacological methods to promote bowel regularity and function.

**Recommendation 10**

That education for health professionals includes the use of non-pharmacological methods to promote bowel regularity and function.

Effective strategies to meet recognized needs associated with continence aids were found to be:

- Selection and trial of appropriate aids;
- Carer education in optimal use of the continence aid;
- Provision of information regarding supply of aids;
- Referral to relevant schemes to assist with supply of continence aids.

**Recommendation 11**

That, prior to the use of continence aids, health care professionals ensure that an appropriate aid has been selected and that the carer has been educated in its use. Furthermore, they should ensure that referrals have been made to a relevant supply scheme.

**5.6 Carer Use of Educational Resources**

Compliance with viewing the videotape and/or reading the fact sheets was satisfactory in most (90%) of the participants. Amongst the other 10%, visual deficits, other caregiving priorities and limited access to a video player were given as reasons for not using one or both of the educational materials. The increase in post-test scores for this cohort is likely to be associated with the ongoing support, discussion and clarification of issues at each visit provided by the registered nurse continence advisor.
5.7 Experience of Caregiving

There was a small difference in the pre and post-test mean scores for the Experience of Caregiving Questionnaire. While this could indicate a decreasing stress burden level, the difference is not statistically significant. In order to detect changes at a statistically significant level of 0.05 it would be necessary to have a much larger sample. To detect such a difference at an alpha of 0.05 with a par 0.8 would require a sample of 2060 cases.

Recommendation 12

That for future use the Experience of Caregiving questionnaire be revised in relation to the wording and scaling of the questionnaire to make it more sensitive to the kind of changes noted.

5.8 Carer Knowledge

Pre-testing of carer knowledge indicated a high knowledge level in relation to cognitive and physiological factors that can cause faecal incontinence. Conversely, there was a low knowledge level regarding strategies to promote and maintain faecal continence and factors other than dementia that can cause faecal incontinence. T test analysis of total scores post-test verified that the knowledge level of carers had increased over the duration of the project, and that this had not occurred by chance.

Comparisons of the pre and post-test Carer Knowledge Questionnaire scores indicated an increase in knowledge in all but one question. The exception to this trend of increased knowledge was the question which tested knowledge on whether persons with dementia may have difficulty in finding the toilet. A high level of correct responses (82.1%) for this area was in existence at pre-test, a result that can be directly attributed to personal experiences gained throughout the role of carer. This percentage remained the same on post-testing.

During the collection of the clinical data, many carers gave the impression that they believed there was nothing that could be done to address bowel problems and accepted it as an expected consequence of dementia. Studies indicate there is community reluctance to report problems with bowels and bowel control to health professionals related to the ‘taboo’ nature of the subject (Kalantar et al., 2002; Prosser & Dobbs, 1997). Carer perceptions that faecal incontinence is a normal and accepted part of the disease process may provide a further rationale for their reluctance to address bowel problems.

Recommendation 13

That education for carers of people with dementia includes specific information regarding the effectiveness of pro-active approaches
in achieving and maintaining faecal continence in people with dementia.

In some cases, carers’ beliefs that faecal incontinence was expected and unable to be reversed had been reinforced by information received from health professionals. The study by Kalantar et al. (2002) suggests that health care providers’ lack of interest in faecal incontinence may be related to their own perception that little can be done other than to provide anti-diarrhoeal agents and incontinence pads. Reinforcement of this belief by healthcare providers is in contrast to the current available literature, which supports simple strategies as interventions to enhance bowel control (Cheetham, Kenefick & Kamm, 2001; Kamm, 1998; Norton, 1997), and specifically for people with dementia, the promotion of external triggers to facilitate continence (Hutchinson et al., 1996).

Recommendation 14

That a study be conducted on the impact of the personal beliefs of carers and health professionals on the expected levels of continence for persons with dementia.

Recommendation 15

That education of health professionals includes specific information regarding the effectiveness of pro-active approaches in achieving and maintaining faecal continence in people with dementia.

Pre-testing of Set 1 scores indicated that knowledge deficits were related to factors that could contribute to promoting and maintaining faecal continence. These deficits included the required daily amount of fibre in the diet, the impact diuretics can have on bowel motions, the value of pear juice in promoting regular bowel habits and knowledge of the impact of poor fitting dentures or poor condition of teeth on bowel function. There was also a low level of knowledge regarding the potential effects of constipation on levels of confusion and faecal continence. All of these factors can be ameliorated by simple strategies.

Four areas of knowledge change are of particular interest. Post-test correct responses indicated an increase in knowledge in relation to:

- factors that contribute to faecal continence;
- constipation and its implications for people with dementia;
- strategies that can assist with promoting and maintaining faecal continence; and
- factors other than dementia that can impact on maintaining optimal bowel function.

In relation to grouped responses, increase in knowledge was supported by t test analysis revealing significant change in 6 of the 7 areas. These were:
• cognitive and physiological change;
• fluid intake;
• dietary fibre;
• medication;
• environment; and
• management and coping.

The area of exercise and activity did not reveal significant change between pre and post-testing. A high knowledge level (87.5% correct response) pre-test for this item and a post-test correct response of 95%, indicated that the role of exercise in promoting regular bowel opening was already well known prior to educational intervention.

The overall results of post-test scores support a greater comprehension of the relevance of the promotion and maintenance of faecal continence for people with dementia, increased awareness of factors other than dementia that can impact on bowels and an increased awareness of strategies that can be implemented to assist with promoting and maintaining faecal continence.

**Recommendation 16**

That the specifically developed carer focused educational materials be adapted for multi-media use and widely disseminated amongst carers, support groups and health professionals.

### 5.9 Continence Status Post Interventions

The faecal continence status of the persons with dementia, did not demonstrate overall improvement following educational interventions directed at their caregivers. Although faecal incontinence levels increased, there were improvements noted within 2 of the 3 groups that were collectively recognized as being continent (faecally continent, faecally continent with assistance and faecal smearing).

It was demonstrated (Figure 4.26), that the number with faecal smearing was reduced following education of carers. An effect of this was an increase in faecally continent persons with dementia when compared to pre-test continence levels. Part of the education provided within the project included information on dietary fibre and environment. Literature supports the role of dietary fibre in bulking stools, thereby making the stools firmer and increasing the likelihood of being able to hold on until getting to the toilet (Bliss et al., 2001). Furthermore, fibre has a tendency to normalize defecation frequency to one bowel movement daily and gastrointestinal transit time to 2 to 4 days (Marlett et al., 2002). Additionally, environmental strategies outlined within the video and fact sheets may help persons with dementia to find and recognize the toilet, further increasing the likelihood of being able to hold on until getting to the toilet (Hutchinson et al., 1996).
Recommendation 17

That carers be assisted to recognise faecal smearing as a form of faecal incontinence that can be ameliorated by simple strategies.

During the collection of the clinical data, it was noted that multiple variables not measured in this project may have been associated with the increase in faecal incontinence. These variables include: deterioration of health status of either the carer or person with dementia; individual behavioural problems related to dementia; length of time since diagnosis of dementia; the level of carer stress and burden; and the type of coping strategies utilized by the carer. Each of these can impact on the implementation and success of strategies to promote and maintain bowel control.

Recommendation 18

That the impact of specific variables on implementation of faecal continence promotion and maintenance strategies become an area for future research.

5.10 Limitations

The number of participants within the study was small. There was no control group which did not receive the educational intervention. Additionally, the combined interventions of the video, fact sheets and registered nurse’s ongoing support, discussion and clarification make it impossible to differentiate the effects of each on knowledge change. The long-term impact on the promotion and maintenance of faecal continence, and / or any delay in institutionalization from the educational intervention is unknown related to the short duration of the study.

Recommendation 19

That the efficacy of the educational intervention, in combination with nursing support, be further tested over a longer time frame.

The Carer Knowledge Questionnaire was specifically developed for the study and therefore there is no prior evidence of its reliability and validity.

Recommendation 20

That, prior to any further use, the Carer Knowledge Questionnaire be further validated.
5.11 Summary of Recommendations

The findings of this study support the primary recommendation:

Recommendation 16
That the specifically developed carer focused educational materials be adapted for multi-media use and widely disseminated amongst carers, support groups and health professionals.

All of the other recommendations are listed here under the grouped headings of carer education, health professionals and further research.

5.11.1 Carer education

Recommendation 1
That education for carers of people with dementia stresses the importance of implementing pro-active strategies for maintaining and improving faecal continence.

Recommendation 2
That education for carers of people with dementia includes specific information regarding recommended daily intakes of fluid and dietary fibre, optimal levels of activity and exercise and possible environmental modifications.

Recommendation 3
That education for carers of people with dementia includes specific strategies to ensure that the person with dementia is able to achieve recommended daily intakes of fluid and dietary fibre.

Recommendation 4
That education for carers of people with dementia includes specific strategies to ensure that the person with dementia is able to achieve and maintain optimal levels of activity and exercise within their limitations and that these strategies address referral to appropriate programs.

Recommendation 5
That education for carers of people with dementia includes specific information regarding environmental modification, with emphasis on relevant contextual and individual factors.

Recommendation 6
That the Bristol Stool Form Scale be used in education for carers of people with dementia to increase knowledge of optimal bowel function.
Recommendation 7
That the use of a footstool to facilitate correct toileting position not be recommended for people with dementia who toilet independently.

Recommendation 8
That bowel habit training not be recommended as a strategy for use in some people with dementia.

Recommendation 9
That education for carers of people with dementia emphasises the use of non-pharmacological methods to promote bowel regularity and function.

Recommendation 13
That education for carers of people with dementia includes specific information regarding the effectiveness of pro-active approaches in achieving and maintaining faecal continence in people with dementia.

Recommendation 17
That carers be assisted to recognise faecal smearing as a form of faecal incontinence that can be ameliorated by simple strategies.

5.11.2 Health professionals

Recommendation 10
That education for health professionals emphasises the use of non-pharmacological methods to promote bowel regularity and function.

Recommendation 11
That, prior to the use of continence aids, health care professionals ensure that an appropriate aid has been selected and that the carer has been educated in its use. Furthermore, they should ensure that referrals have been made to a relevant supply scheme.

Recommendation 15
That education of health professionals includes specific information regarding the effectiveness of pro-active approaches in achieving and maintaining faecal continence in people with dementia.
5.11.3 Further research

Recommendation 12
That for future use the Experience of Caregiving questionnaire be revised in relation to the wording and scaling of the questionnaire to make it more sensitive to the kind of changes noted.

Recommendation 14
That a study be conducted on the impact of the personal beliefs of carers and health professionals on the expected levels of continence for persons with dementia.

Recommendation 18
That the impact of specific variables on implementation of faecal continence promotion and maintenance strategies become an area for future research.

Recommendation 19
That the efficacy of the educational intervention, in combination with nursing support, be further tested over a longer time frame.

Recommendation 20
That, prior to any future use, the Carer Knowledge Questionnaire be further validated.
6.0 ADAPTABILITY OF EDUCATIONAL INTERVENTIONS

It is known from pre-testing of carer knowledge that there was an overall low knowledge level in relation to factors that contribute to faecal continence, constipation and its implications for people with dementia, awareness of strategies to assist with promoting and maintaining faecal continence and factors other than dementia that can impact on promoting and maintaining optimal bowel function.

Following educational intervention, the results have indicated an increase in knowledge for each of the low knowledge areas identified at pre-test. This outcome suggests the effectiveness of the video and fact sheets as educational interventions in enhancing carer knowledge on the promotion and maintenance of continence. These educational interventions were well received by participants who commented favourably on the appropriateness and information level of the content and on the format, which normalized a sometimes difficult subject. Although not all strategies highlighted within the video or fact sheets were applicable to everyone, knowledge of their existence may facilitate proactive carer practices in the future.

Providing education to carers of persons with dementia on the promotion and maintenance of faecal continence can facilitate a proactive problem solving approach within the caregiving role. The Almberg, Graafstrom & Winblad, (1997b) study reinforces the importance of a proactive approach by carers, through its finding that carers who utilize a problem focused coping strategy cope better than carers who utilize emotion focused coping strategies. Enhanced carer coping is facilitated by this proactive, educative type of approach.

Knowledge of these strategies is important because they can assist in the prevention of faecal incontinence. Implementation of strategies that promote and maintain faecal continence can benefit carers by diminishing the likelihood of faecal incontinence and the associated stress and burden for caregivers when this is present, thereby preventing and / or delaying institutionalization.

When faecal continence is promoted, the aim is that faecal incontinence episodes will be reduced or eliminated. Subsequent benefits of this may include a reduction in the stress associated with faecal incontinent episodes and / or extremes of behaviour, enhancing quality of life for the person with dementia and the carer (Gerdner et al., 1996; Ghatak, 1994; Jenkins, 2000).

Expanding the target audience of the educational materials to include health care providers, may raise awareness of the value and importance of promoting and maintaining faecal continence and ways to achieve this. Promoting this knowledge amongst health care providers can facilitate the promotion and maintenance of faecal continence for persons with dementia, with whom health professionals come in contact in their day-to-day practice.

The conduct of this project has provided opportunities to identify the frequency and nature of actual and potential faecal continence problems amongst a group of people with dementia being cared for at home. It has resulted in the production of widely applicable carer focused educational resources on maintaining faecal continence.
addition, it has tested the efficacy of an early intervention program to ameliorate faecal continence problems, particularly the enhancement of carer knowledge.

This project has been successful in achieving its objectives of producing carer focused educational resources and educating and supporting home carers in enhancing faecal continence in people with dementia. It was not successful in improving levels of faecal continence. Even so, these levels did change minimally, with a qualitative improvement in the continent group through the reduction of faecal smearing.

The outcomes of this project support the efficacy of the educational interventions of video, fact sheets and registered nurse discussion and clarification in increasing carer knowledge on the promotion and maintenance of faecal continence for persons with dementia being cared for at home.
APPENDIX 1

Project Team
Project Team

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Australian Catholic University

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Project Officer

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Acknowledgements

We wish to acknowledge Ms Marie Ku, who forged the links between the two participating organisations and played a critical role in developing the ideas underpinning this project.

Additionally, a special thankyou is extended to Mr William Foster, for his guidance and direction with data analysis.
APPENDIX 2

Faecal Continence Assessment Tool
# FAECAL CONTINENCE PROGRAM

## FAECAL CONTINENCE ASSESSMENT TOOL

<table>
<thead>
<tr>
<th>DATE</th>
<th>____________________________________________________</th>
</tr>
</thead>
<tbody>
<tr>
<td>NAME</td>
<td>____________________________________________________</td>
</tr>
<tr>
<td>ADDRESS</td>
<td>____________________________________________________</td>
</tr>
<tr>
<td>PHONE</td>
<td>____________________________________________________</td>
</tr>
<tr>
<td>AGE</td>
<td>____________________________________________________</td>
</tr>
<tr>
<td>HOME CARER</td>
<td>____________________________________________________</td>
</tr>
<tr>
<td>RELATIONSHIP</td>
<td>____________________________________________________</td>
</tr>
<tr>
<td>CARER AGE</td>
<td>____________________________________________________</td>
</tr>
<tr>
<td>LIVING WITH PARTICIPANT</td>
<td>____________________________________________________</td>
</tr>
<tr>
<td>EMPLOYMENT STATUS OF CARER</td>
<td>____________________________________________________</td>
</tr>
<tr>
<td>CARER PHYSICAL RESTRICTIONS ON ROLE</td>
<td>__________________________</td>
</tr>
<tr>
<td>CARER MEDICAL RESTRICTIONS ON ROLE</td>
<td>__________________________</td>
</tr>
</tbody>
</table>

Department of Health and Aged Care – Faecal Continence Grants Program 58
### MEDICAL HISTORY

<table>
<thead>
<tr>
<th>Medical Condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia</td>
</tr>
<tr>
<td>Parkinson’s Disease</td>
</tr>
<tr>
<td>Multiple Sclerosis</td>
</tr>
<tr>
<td>CVA</td>
</tr>
<tr>
<td>Spinal disease / injury</td>
</tr>
<tr>
<td>Diabetes</td>
</tr>
<tr>
<td>Hypertension</td>
</tr>
<tr>
<td>Osteoporosis</td>
</tr>
<tr>
<td>Osteoarthritis</td>
</tr>
<tr>
<td>Rheumatoid Arthritis</td>
</tr>
<tr>
<td>Haemorrhoids</td>
</tr>
<tr>
<td>CCF</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

### SURGICAL HISTORY

<table>
<thead>
<tr>
<th>Surgical Procedure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urethral dilation</td>
</tr>
<tr>
<td>Bladder neck surgery</td>
</tr>
<tr>
<td>Hysterectomy</td>
</tr>
<tr>
<td>Haemorrhoidectomy</td>
</tr>
<tr>
<td>TUR prostate</td>
</tr>
<tr>
<td>Pelvic floor repair</td>
</tr>
<tr>
<td>Fissures / tears</td>
</tr>
<tr>
<td>Anatomical abnormality</td>
</tr>
<tr>
<td>Gastrointestinal surgery</td>
</tr>
<tr>
<td>Anorectal surgery</td>
</tr>
<tr>
<td>Colonoscopy</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

### Relevant family history

### Investigations

### MEDICATIONS

<table>
<thead>
<tr>
<th>Name</th>
<th>Dose</th>
<th>Frequency</th>
<th>Use / Effect</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Current laxative or aperient use</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Medicines which may affect bowel elimination</th>
</tr>
</thead>
</table>
### Past history of laxative use:
- Self medicates
- Assisted by:

### COGNITIVE FUNCTION

**MMSE SCORE:** _________________________________

**COMMENTS:** _____________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

### Is client depressed?

<table>
<thead>
<tr>
<th>Hearing</th>
<th>Normal</th>
<th>Impaired</th>
<th>Hearing aid/s</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speech</td>
<td>Normal</td>
<td>Impaired</td>
<td></td>
</tr>
<tr>
<td>Eyesight</td>
<td>Normal</td>
<td>Impaired</td>
<td>Glasses worn</td>
</tr>
</tbody>
</table>

**Comments:**

### Continent of urine

<table>
<thead>
<tr>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Continent of urine</td>
<td></td>
</tr>
</tbody>
</table>

**Type of urinary incontinence**
CURRENT BOWEL HABITS – (REFER TO BRISTOL STOOL CHART)

Bowel opening frequency: ______________________________________________________

Bowel opening time: __________________________________________________________

Stool colour: ________________________________________________________________

Stool Consistency

<table>
<thead>
<tr>
<th>Hard pellets</th>
<th>Soft / formed</th>
<th>Runny / loose</th>
<th>Smearing</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Other:

<table>
<thead>
<tr>
<th>Amount</th>
<th>Large</th>
<th>Mod</th>
<th>Small</th>
<th>Smearing</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Sensation to bowel elimination

<table>
<thead>
<tr>
<th>Awareness</th>
<th>Sometimes aware</th>
<th>Not aware</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aware</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Toilet use

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Sometimes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

What factors influence use of toilet?

Symptoms

<table>
<thead>
<tr>
<th>Urgency</th>
<th>Diarrhoea</th>
<th>Need for manual removal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Straining</td>
<td>Mucous</td>
<td>Recurrent abdominal distension</td>
</tr>
<tr>
<td>Difficulty/Inability to defecate</td>
<td>Rectal Bleeding</td>
<td>Abdominal pain</td>
</tr>
<tr>
<td>Pain on defecation</td>
<td>Digitation required</td>
<td>Continent of flatus</td>
</tr>
<tr>
<td>Backache</td>
<td>Loss of appetite</td>
<td>Headache / sweating</td>
</tr>
</tbody>
</table>

Soiling / faecal incontinence frequency:

PREVIOUS BOWEL HABITS (include special rituals / tricks preceding BO)
### Toileting Pattern

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Sometimes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does client toilet him / herself?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does client recognize need to toilet?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does client initiate toileting?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is client able to find the toilet?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is client able to get to the toilet in time?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is client unwilling to be toileted?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is client able to recognize the toilet?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does client hide soiled pads / clothes?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does client attempt to clean up episodes of faecal incontinence?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can bowel motions be found on other receptacles e.g. floor, taps, walls, toilet seat.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the toilet close to where the person sleeps?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Toileting Ability

<table>
<thead>
<tr>
<th>Task</th>
<th>Independent</th>
<th>Prompt</th>
<th>Assist</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADJUST CLOTHES</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>USE TOILET PAPER</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WASH HANDS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CHANGE AIDS</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Toilet environment

<table>
<thead>
<tr>
<th>Feature</th>
<th>Yes</th>
<th>No</th>
<th>Sometimes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Toilet seat raiser</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Commode</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lever handles</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coloured toilet water</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Well marked door</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Way finding cues</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Locks on doors</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hazards / obstructions</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bright even lighting</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grab rails</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wooden toilet seat</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sensor light</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Door opens outward</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coloured toilet seat</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Receptacles mistaken for toilet</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Yes</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>-----</td>
<td>-----</td>
<td></td>
</tr>
<tr>
<td>Is the toilet easily accessible?</td>
<td>Yes</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Is commode in an accessible location if required?</td>
<td>Yes</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Is the toilet at an appropriate height?</td>
<td>Yes</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Is there adequate privacy?</td>
<td>Yes</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Is client restless / agitated before a bowel action?</td>
<td>Yes</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>What other non-verbal signs are noted?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is the client able to sit on the toilet and stay on the toilet?</td>
<td>Yes</td>
<td>No</td>
<td></td>
</tr>
</tbody>
</table>

**Continence aids in use**

<table>
<thead>
<tr>
<th>Aids in Use</th>
<th>Day aid:</th>
<th>Night aid:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are they satisfactory?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>If ‘No’ why?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What has been tried, but not successful?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aids supplied through?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### MOBILITY / EXERCISE

<table>
<thead>
<tr>
<th>Ability</th>
<th>Independent</th>
<th>Prompt</th>
<th>Assist</th>
</tr>
</thead>
<tbody>
<tr>
<td>Able to walk</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Able to stand</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Able to transfer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can get to toilet</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Are any aids required?  

- Yes  
- No

If YES what aids are needed?

Is client chair fast?  

- Yes  
- No

Is client bed fast?  

- Yes  
- No

Is client’s dexterity  

- Normal  
- Limited  
- Poor

Regular exercise?  

- Yes  
- No

Describe?

Activities enjoy doing?

Attendance at day respite?

In home respite?

Behavioural problems or concerns?

Comments:
### DIET AND FLUID INTAKE

<table>
<thead>
<tr>
<th>Approximate daily fluid intake (amount)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Types of fluids (number of cups)</td>
<td></td>
</tr>
<tr>
<td>- Water</td>
<td></td>
</tr>
<tr>
<td>- Tea</td>
<td></td>
</tr>
<tr>
<td>- Coffee</td>
<td></td>
</tr>
<tr>
<td>- Alcohol</td>
<td></td>
</tr>
<tr>
<td>- Other</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Is appetite</th>
<th>Good</th>
<th>Average</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Servings per day</td>
<td>Fruit</td>
<td>Vegetables</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Bread</td>
<td>Cereal</td>
<td></td>
</tr>
</tbody>
</table>

**Other:**

<table>
<thead>
<tr>
<th>Foods avoided (include reason)?</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Fibre supplements taken?</td>
<td>Yes</td>
</tr>
<tr>
<td>Type:</td>
<td></td>
</tr>
<tr>
<td>Does client feed him / herself?</td>
<td>Yes</td>
</tr>
<tr>
<td>Does client have difficulty swallowing?</td>
<td></td>
</tr>
<tr>
<td>Does client have any teeth / gum problems?</td>
<td>Yes</td>
</tr>
</tbody>
</table>

If Yes, describe:

<table>
<thead>
<tr>
<th>Teeth</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do dentures fit securely?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Do dentures fit securely?</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>
## PHYSICAL EXAMINATION

### Is the client?

<table>
<thead>
<tr>
<th>Thin</th>
<th>Normal</th>
<th>Overweight</th>
<th>Obese</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Is the client’s skin impaired / excoriated?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

If yes, where?

### Abdomen

<table>
<thead>
<tr>
<th>Distended</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symmetrical</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Scars present</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Discomfort / pain present</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

Describe

Does client have prolapse?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

Does client have rectal bleeding?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

Does client have faecal impaction?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

**PR Examination (optional)**

<table>
<thead>
<tr>
<th>Attended</th>
<th>Not attended</th>
</tr>
</thead>
</table>

Findings?

Other findings?

---
PERCEPTION OF PROBLEM

PERSON:

_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

CARER:

_____________________________________________________________________
_____________________________________________________________________
_____________________________________________________________________

SUMMARY OF PROBLEMS IDENTIFIED

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

ACTION TO BE TAKEN

___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________
___________________________________________________________________________________

NAME: ______________________________________________     DATE: ___________________
RN SIGNATURE: _______________________________________

Department of Health and Aged Care – Faecal Continence Grants Program
APPENDIX 3

Bowel Management Program
National Continence Management Strategy

"Care Plan.xls"
APPENDIX 4

Summary Sheet
BOWEL MANAGEMENT CARE PLAN

NAME: _____________________________________________

DIET AND FLUID

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

EXERCISE / MOBILITY

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

ENVIRONMENT

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

MEDICATION

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________
TOILETING

CONTINENCE AIDS

BEHAVIOURAL INTERVENTIONS

TAKING CARE OF CARE GIVER

BOWEL CHART

A bowel chart helps to establish a record of current bowel patterns. Attached is a sheet to record bowel actions.

- Please record bowel actions on this sheet.

- Use the comments section to record episodes of incontinence or soiling. You may want to note associated events.
  e.g.: before/after breakfast, medications, different environment.
APPENDIX 5

Bowel Record Chart
# FAECAL CONTINENCE PROGRAM

## BOWEL RECORD CHART

<table>
<thead>
<tr>
<th>Name:</th>
<th>Month:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>DATE</th>
<th>TIME</th>
<th>AMOUNT</th>
<th>CHARACTERISTICS</th>
<th>COMMENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>E.g. L = large</td>
<td>(1-7) (See Bristol Stool Chart)</td>
<td>E.g. continent, incontinent</td>
</tr>
<tr>
<td></td>
<td></td>
<td>M = medium</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>S = small</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Review date: ________________________ Signature RN: ________________________

Department of Health and Aged Care – Faecal Continence Grants Program 81
APPENDIX 6

Bristol Stool Form Scale
APPENDIX 7

Carer Knowledge Questionnaire
## CARER KNOWLEDGE QUESTIONNAIRE

**INSTRUCTIONS:**

*Questions 1 to 14 - There are three options to choose from.*

*Please place a tick in the box you consider appropriate for you at this point in time.*

<table>
<thead>
<tr>
<th></th>
<th>AGREE</th>
<th>UNSURE</th>
<th>DISAGREE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Changes in the brain that occur with dementia can interfere with the ability to control bowels?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. People with dementia may have an inability to recognize the need to go to the toilet?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. People with dementia may not be able to wait until it is appropriate to go to the toilet?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. People with dementia may not be able to find the toilet?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. People with dementia may not be able to recognize the toilet?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Changes to the home environment can affect identification of the toilet in people with dementia?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. People with dementia may be unable to use the toilet properly?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Constipation can lead to loss of bowel control?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Poor fitting dentures or poor condition of teeth can impact on bowel function?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Exercise helps keep bowels regular?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Increased confusion in people with dementia may be associated with constipation?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Fibre is important in the diet?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Tea and coffee do not affect water loss from the body?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
14. Pear juice contains a natural laxative called sorbitol and can help keep bowels regular?

<table>
<thead>
<tr>
<th>Questions 15-25</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please write your response to each of the following questions. If there is any thing you don’t understand ask the Registered Nurse for assistance.</td>
</tr>
</tbody>
</table>

15. How much fluid do you need to keep bowels regular?

______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

16. What things can you try to increase fluid intake for a person with dementia?

______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

17. How does fibre help bowel function?

______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

18. How much dietary fibre is needed each day?

______________________________________________________________________________
### Questions

19. What types of food are high in fibre?

20. What effect can medication have on bowel function?

21. What things do you know of to promote independence in toileting for people with dementia?

22. What non-verbal signs may indicate the need to toilet in a person with dementia?
23. Identify some possible causes of a loss of bowel control in a person with dementia?

_____________________________________________________________________________

_____________________________________________________________________________

_____________________________________________________________________________

24. How can a carer manage any episodes of loss of bowel control in a person with dementia?

_____________________________________________________________________________

_____________________________________________________________________________

_____________________________________________________________________________

25. Where can you seek help for bowel problems?

_____________________________________________________________________________

_____________________________________________________________________________

_____________________________________________________________________________

Caregiver Name: ____________________________________________


Pre test          Post test


THANK YOU FOR COMPLETING THE QUESTIONNAIRE.

Please give the completed questionnaire to the Registered Nurse.
APPENDIX 8

Experience of Caregiving Questionnaire
## EXPERIENCE OF CAREGIVING QUESTIONNAIRE

### INSTRUCTIONS:

For each of the following questions there are five possible responses. Could you please place a tick in the box that is most applicable in your experience of caregiving?

<table>
<thead>
<tr>
<th></th>
<th>NEVER</th>
<th>RARELY</th>
<th>SOMETIMES</th>
<th>FREQUENTLY</th>
<th>ALWAYS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do you feel that you need a holiday (a long – term break from caring)?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Do you worry about safely leaving your dependant on his or her own?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Do you find it difficult to get away for a break for a few hours?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Has your social life been affected by caring?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Is your sleep disrupted by your dependant?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Do you have family arguments / difficulties associated with your present situation?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Have your financial circumstances changed or your standard of living been reduced as a result of caring?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Do you have difficulty in continuing your relationships, e.g. having visitors or meeting friends, due to your caring commitments?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Do you find that you’re caring responsibilities adversely affect other aspects of your life, e.g. your role as a parent / grandparent, your employment/other commitments?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Do you have to undertake care giving tasks that you feel are beyond your capabilities?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Has your own physical health suffered as a result of caring?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Do you feel there will be no end to your problems?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
13. Do you feel you can no longer cope with your situation?  
14. Do you feel overwhelmed by your situation?  
15. Do you feel trapped in the caring role?  
16. Do you feel that you are alone in coping with your caring situation?  
17. Do you find it distressing that your dependant has changed so much from his or her former self?  
18. Do you have feelings of grief and loss associated with your caring role?  
19. Do you find yourself becoming tearful and crying?  
20. Do you feel exhausted and demoralized in your caring role?  
21. Are you depressed about your situation?  
22. Do you feel like giving up caring?  
23. Do you feel embarrassed by your dependant?  
24. Do you feel frustrated with your dependant?  
25. Do you get cross and angry with your dependant?  
26. Are you resentful about the change in the quality of your own life / missed life opportunities?  
27. Are you emotionally distant from your dependant?  
28. Do you view caring for your dependant as being like caring for a child?  
29. Do you have feelings of guilt associated with your caring role?  
30. Do you feel helpless and as if things are outside of your control in your situation?  
31. Do you have a sense of achievement or fulfillment as a result of caring?  
32. Do you have a sense of purpose and direction in your caring role?  
33. Do you derive personal satisfaction and reward from you’re caring?  
34. Do you have feelings of positive self-worth / self esteem arising from caring?
### 35. Do you feel that being a carer has provided an opportunity for personal growth and development?  

<table>
<thead>
<tr>
<th>NEVER</th>
<th>RARELY</th>
<th>SOMETIMES</th>
<th>FREQUENTLY</th>
<th>ALWAYS</th>
</tr>
</thead>
</table>

### 36. Do you feel that caring is a positive way of expressing your love and affection for the person you care for?  

### 37. Do you feel that you adopt a positive, problem-solving approach to caring?  

### 38. Do you feel that you manage your stress well and overcome it?  

### 39. Do you feel the help you receive from services, family and friends has enabled you to carry on in the caring role?  

### 40. Do you feel hopeful about your future?  

<table>
<thead>
<tr>
<th>NEVER</th>
<th>RARELY</th>
<th>SOMETIMES</th>
<th>FREQUENTLY</th>
<th>ALWAYS</th>
</tr>
</thead>
</table>

### 41. Reflecting on your overall situation, all in all would you say you are:  
(Please tick one box)

- [ ] Coping well with no stress  
- [ ] Coping fairly well / with a small amount of stress  
- [ ] Just about coping / with a great deal of stress  
- [ ] Having difficulty coping / with a great deal of stress  
- [ ] Finding it almost impossible to cope / with an extremely high level of stress  

**Caregiver’s Name:** ____________________________________________  
**Pre test** / **Post test**  

**THANK YOU FOR COMPLETING THIS QUESTIONNAIRE.**  
Please give the completed questionnaire to the Registered Nurse at next visit to your home.  

APPENDIX 9

Video
APPENDIX 10

Fact Sheets
References


Anti, M., Pignataro, G., Armuzzie, A., Valenti, A., Iascone, E., Marmo, R., et al. (1998). Water supplementation enhances the effect of high-fiber diet on stool frequency and laxative consumption in adult patient with functional constipation. *Hepato-gastroenterology, 45*(21), 727-732.


Ferguson, L.R. & Harris, P.J. (1997). Do resistant starches as well as dietary fibers protect against colorectal cancer? *Journal of Environmental Pathology, Technology and Oncology, 16*(4), 335-341.


