Ameliorating incontinence in older people with cognitive impairment:  
Eight case studies

Report to Department of Health and Ageing on the results of a study funded by  
an Innovative Grant originally entitled:  
Use of cues to minimise incontinence in elderly people with cognitive impairment

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Executive summary

Interventions were undertaken in a small series of cases of incontinence associated with cognitive impairment in elderly people. The project was developed for two reasons, firstly as a means of adding a dementia-specific learning technique originally derived from memory research to the current repertoire available with incontinence in dementia. Secondly, by demonstrating application of these techniques to a specific problem, it was hoped that more memory researchers might be tempted out of the laboratory to apply their findings to the real-life and often severe problems which plague people who suffer memory impairment.

Two issues changed the focus of the project. One was enormous difficulty in recruiting cases which fitted the selection criteria. This was totally unexpected. In the end eight cases were attempted and, of these, three had to be aborted: one because the participant broke her leg; one because the carer withdrew the participant from the project; and, in the remaining case, because the participant had only a slight problem and was not motivated to solve it. We consider that we had a reasonable chance of success in two of these aborted cases but will never know.

The other issue was the fact that quite basic causes of incontinence had often been ignored, even when participants had been seen by continence advisors. As a result, the interventions were extremely varied. In only one of the completed cases was the dementia-specific teaching technique around which the project was planned the primary intervention, though it played a part in at least one other. Other cases included changing the drinking habits of participants, changing their toileting habits, and/or removing a sense of helplessness and motivating them to address their incontinence.

Accordingly, the objectives of the study were changed somewhat, and the report has become a detailed case-series. In the five cases which were completed, we were successful in reducing or eliminating incontinence. In four of these cases there were substantial other benefits, including less time on laundry and use of pads, improvements in quality of life and/or depression scores, and also being able to put carers in touch with support services of which they had been unaware. In one of the cases, incontinence resumed after a few months following a long holiday by the
person with dementia, and we were unable to ameliorate the problem the second time around.

Outcome of the project is therefore more disappointing than we expected, with a success rate of 62%, given that three out of the eight cases had to aborted. We were successful in all the cases we were able to complete but it is more parsimonious to treat aborted cases as failures, even though we believe we had a real chance of ameliorating the situation in two of them. There are too few cases to draw definitive conclusions, apart from the difficulty of recruitment. This pilot study does, however, suggest at a minimum that incontinence can cause the same distress - including shame and depression - to people with cognitive impairment as it does to people who are unimpaired. In our sample there was evidence that many of these cases had been inadequately assessed, and that some of the advice given by continence advisors to people with significant cognitive impairment was impractical, but it is impossible to generalise from such a small sample

Acknowledgements

The authors gratefully acknowledge the participation of people with cognitive impairment and their carers who took part in this case-series. We also wish to thank the Ageing and Aged Care Division of the Australian Government Department of Health and Ageing, not only for funding the study, but also for showing considerable forbearance in extending its timelines when we had difficulty recruiting cases.
Introduction

Incontinence is often regarded as an inevitable and untreatable consequence of ageing. It is worthy of attention because it is neither inevitable nor, in many cases, untreatable and also because it has a significant psychosocial impact on older people. It is intrinsically distressing and it impacts significantly on daily activities, ability to go out, and interpersonal relationships – including sexual activity (Burgio, 1994). It is likely to be equally distressing for people with dementia, though they are not often asked. It is known that home carers are also distressed by the consequences of the person with dementia being incontinent and, for this reason, incontinence is a major predictor of the decision by family members to relinquish care (Resnick, 1995). In residential aged care, incontinence in residents with dementia involves significant costs in staff time and materials (Ouslander & Schnelle, 1993).

Incontinence in older people usually has primarily physical causes but, in people with dementia, there is clearly a subset of cases where cognitive impairment plays either an additive or even directly causal role. This is manifest in the fact that the prevalence of incontinence in dementia is much higher than in the general aged population (Skelly & Flint, 1995) but that non-medical interventions such as prompted voiding have a significant impact (Colling, Ouslander, Hadley, Eisch, & Campbell, 1992). Common causes of the way cognitive impairment can affect incontinence include: inability to find or sometimes even seek the toilet; toileting in places which resemble suitable receptacles (for example the wash basin or waste-paper bins) or where earlier life patterns are triggered (for example using the garden); and/or failure to recognise or respond to the physiological signals that it is time to go.

The first author has published a number of articles on teaching techniques known as the methods of fading cues and spaced retrieval (eg. Bird, 2001). The publications show, firstly, how people with mild to moderate dementia can be taught using these techniques to associate a cue or cues with a behaviour and then act on those cues where they are encountered in the environment (eg. a sign), or when they are activated (eg. a beeper). Though cues are widely advocated in dementia care, they are useless unless the person with dementia can be induced to attend to them, learn and remember what they mean, and then act on them when required (Bird, 2001). Effective methods to teach patients to do this have been slow to penetrate clinical practice.
Secondly, these publications show adaptation of spaced retrieval and fading cues to behaviours which distress carers, including incontinence. For example, a case of chronic faecal incontinence in a woman with dementia was ameliorated by using these techniques to teach her that a customised beeper, set to sound every two hours, meant that it was time to go to the toilet (Bird, 1998). This case also involved a visual cue – a well-lit commode near the bed at night. In another published case (Bird, Alexopoulos, & Adamowicz, 1995), we taught a man with urinary incontinence and dementia to follow a chain of signs to the toilet.

The original proposal for this project therefore sought, through a series of interventions, to investigate the extent to which these learning techniques could be added to existing practical methods for management of incontinence, in those cases where cognitive impairment was a causal factor. It was also hoped that publication of results in an experimental psychology journal might help encourage more cognitive researchers to emerge from the memory laboratory and apply their skills towards alleviating the real-life problems which plague people with memory impairment, including those with dementia.

* Methods

Cases were recruited initially through Community Health and Aged Care Assessment Teams. Criteria for inclusion were: (a) incontinence thought to be at least in part caused by cognitive impairment associated with ageing; and, (b) living in the community with a carer.

We had a number of referrals which did not fit the criteria and, to our considerable surprise, it eventually became clear that recruitment was going to be a major problem. We therefore made contact with the manager of a community home-care team run by a non-government organisation which had a number of potential cases and whose staff were extremely interested in participating. We applied twice for ethical approval to the NGO to undertake these cases but, after a delay of more than 6 months, were
refused. Eventually, in order to make up case numbers within the extended time-line of the project, we recruited the final two cases from an aged residential care facility.

The final total of cases actually commenced was eight. Accordingly, this report is presented as a case series, with the same objective measures applied to each case. Measurement was undertaken at the first assessment, after consent was obtained. Frequency and nature of incontinence incidents was assessed, together with use of incontinence pads and/or frequency and means of washing soiled clothes due to incontinence.

Participants were also given the six question Leeds Depression Scale (Snaith, Bridge, & Hamilton, 1976) which has a possible total of 18, with a clinical cut-off of 6/7. They were given five additional questions assessing the effects on quality of life of incontinence (Fonda, Woodward, D’Astoli, & Fong Chin, 1995), scored on a four-point Likert Scale. There is no clinical cut-off, and one of the original questions, ‘The smell of incontinence bothers me,’ was dropped because early subjects found the question itself offensive. These measures were given via personal interview, utilising a technique developed by Bird, Caldwell, Maller, & Korten (2005) which maximises the chances that people with dementia attend to each question and retain it in memory long enough to consider it on a Likert scale. All outcome measures were given again between six weeks and twelve weeks later.

Cognitive status was assessed at baseline only by the Abbreviated Mental Test (MacKenzie, Copp, Shaw & Goodwin 1996), which has a total score of 12 with scores lower than 9 suggesting that there may be cognitive problems. We also administered the Clock Drawing Test, now widely given as part of routine cognitive assessment because it taps non-verbal functioning, is not threatening, and can be given very quickly. We used the scoring system of Sunderland et al. (1989) which gives a total of 10, with scores below 7 suggesting that there may be cognitive impairment. Level of impairment was also assessed in some cases by informant report using the Clinical Dementia Rating (Morris, 1993), which assesses 6 domains of functioning and uses algorithms to classify participants into no dementia or questionable, mild, moderate, or severe dementia.

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Results: Eight cases of incontinence

Detailed descriptions of the background to each case are presented here, together with interventions employed, and outcomes. Table 1 on Page 17 summarises baseline and follow-up data for each case.

Case 1

D was an 86 year old woman with Alzheimer’s disease living with her very supportive husband in the community. She scored 7 on the Abbreviated Mental Test and 8 on the Clock Drawing Test. Assessment on the Clinical Dementia Rating placed her in the mild dementia range. She was in good physical health and had good insight into both her memory impairment and her incontinence. At baseline, she obtained a score of 7 on the Leeds Depression Scale, placing her in the clinical range.

D had been incontinent of urine for about 2 years and, at baseline measurement, was having accidents 5-6 times a day. Asked about the effect of this, she said she found it embarrassing and that it depressed her. She had been assessed by a continence advisor, and her husband reported that D had been advised to perform pelvic floor exercises several times a day. It was unclear how someone with significant cognitive impairment would be able to learn and remember how to do this, and remember actually to do it. This problem became even more salient when D’s husband reported that, when he reminded D to go to the toilet or do her exercises, it often made her irritated and she refused. D was using a mean of 24 incontinence pads a week, and her husband was sending out about 7 loads of laundry a week.

We used the method of spaced retrieval and fading cues to teach D in a single session to associate a beeper with going to the toilet. After two hours, she reliably went to the toilet every 20 minutes when the beeper sounded. Her husband observed the training, was shown how to set the beeper, given a series of cues to help D remember when the beeper went off, and instructed to slowly increase the interval between beeps. By our follow-up visit one week later, he had bought a louder beeper, and had attached it to D’s blouse. We arranged for the beeper to go off while we were there. D did not appear consciously to register the sound but, nevertheless, got up without prompting and went to the toilet. That is, the association between beeper and going to the toilet had been internalised, and she did not need her husband to prompt her.
At follow-up six weeks later, there had been no incidents of incontinence for two weeks. D’s score on the Leeds Depression Scale had dropped to 4, no longer in the clinical range. She reported no longer feeling depressed or embarrassed. Use of incontinence pads had dropped from 24 a week to 3, and her husband was only sending out about 2 loads of laundry a week.

Case 2
J was a 71 year old woman with Pick’s disease who lived with her husband in the community. She obtained a perfect score on the Clock Drawing Test and 8 on the Abbreviated Mental Test. She fell in the moderate dementia range on the Clinical Dementia Rating. She was in ‘fair’ physical health. She had conscious insight into the difficulties that her impairments caused, including her incontinence. Neither by her own nor her partner’s report was she depressed, though she said that she felt mildly embarrassed by being incontinent.

J had been incontinent for about a year and had a pattern of dry periods and bad days when she tended to flood, often at night. There were also occasional episodes of faecal incontinence. Overall the mean reported by her husband was 2.4 episodes a week though we suspect it was much higher; he was sending out 2 loads of washing a week, spending about 6 hours a week on washing J’s soiled clothing and bedding, and J was using about 14 pads a week. On our first visit, we were able to put J’s husband onto a subsidised incontinence linen service of which he had been unaware. The couple had been visited by a continence advisor, who had given no advice about subsidised linen and recommended pelvic floor exercises - again with no suggestion how applicable this was for someone with significant cognitive impairment.

It quickly became clear that J was drinking very large amounts of undiluted orange juice, in particular in the hours before going to bed. Fluid balance charts showed a strong association between this and flooding incidents. Accordingly, her husband was advised to slowly reduce J’s intake, and also dilute the orange juice. At 6 week follow-up, there had been no incidents of incontinence for two weeks. J was using only 10 pads a week, which her husband put on ‘just in case’. He was spending only
one hour a week on laundry for J, and no longer sending out loads to be done commercially.

J stayed largely dry but, some months later, went on extended respite to stay with her daughter. Unfortunately, whilst there, problems resumed despite advice being given about the strategy we had employed. On J’s return her incontinence problems were as bad as when we were first called in, and there was an increase in faecal incontinence. We were unable to be effective the second time round. It is possible that there had been some deterioration in J’s level of impairment. This was not apparent on cognitive testing but there was some evidence of deterioration in insight. J now showed no concern about being incontinent and mostly denied that it occurred.

**Case 3**

M was an 84 year old woman with a generic diagnosis of dementia living alone in the community. She was mainly looked after by community nurses. She scored 6 on the Abbreviated Mental Test and 5 on clock drawing. We were unable to get the Clinical Dementia Rating completed but reports from home-care staff suggested a mild to moderate level of impairment. M obtained a score in the Leeds depression scale suggesting a clinical level of symptoms, and reported embarrassment and depression about being incontinent. It was unknown how long she had been incontinent as she had only recently come to the attention of support services. In the absence of a live-in carer, we were able to obtain a rough estimate of frequency of accidents (3-4 daily) from the number of soiled under-garments M left in a bucket to soak every day.

When asked about the difficulties incontinence caused, M said that the primary problem was not being able to get to the toilet on time when she felt the urge, suggesting that prompted voiding (with the assistance of a beeper) at shorter intervals than she currently visited the toilet might be a suitable strategy. Unfortunately, just before we were due to commence the intervention, M had a fall and broke her leg. She eventually returned home but we were not able at that time to resume the case. When we were she had gone into care.
**Case 4**

V was a 74 year old woman with a diagnosis of mixed dementia living in her own unit on a farm with her son and daughter-in-law in the main house. V had been incontinent now and again for four years but had recently suffered major deterioration following a hospital stay. At first assessment it became clear that she had been suffering mild delirium, probably due to the anti-cholinergic drugs she was given on discharge. These had been ceased just prior to our visits and she had become less confused. We gave V a few more weeks for the drugs to clear from her system, and were then able to take our baseline measures. She scored 5 on the Abbreviated Mental Test, and was in the ‘mild dementia’ range on the Clinical Dementia Rating. Clock drawing was invalid because of her poor eyesight. Both self report, informant report, and her score on the Leeds depression scale suggested that V was significantly depressed. On initial interview she was open about having memory problems, but appeared to have no insight into the fact that she was incontinent.

Episodes of urinary incontinence were occurring about twice a week and V was using about 5 pads a week. Her daughter-in-law was putting through one load of linen a week soiled by incontinence and also spending at least half an hour a day cleaning up faeces. The urinary problem disappeared after our second visit, when we discussed the problem very frankly and the need to go to the toilet at regular intervals even if V did not feel that she needed to. We prepared to teach her to use a beeper as a reminder but on our follow-up visit she showed that she retained sufficient cognitive capacity to visit the toilet regularly relatively independently. The frank conversation about incontinence had two effects. It forced V to take the problem seriously. It also unfortunately made her start talking about herself as ‘useless’ and ‘a burden’. As a result of our baseline finding that V was already depressed, we had in any case arranged for a geriatrician to see her so that he could advise the GP to trial a course of anti-depressants. (The GP did not like giving psychotropic medication to older people, but agreed to a trial).

The problem of faecal soiling remained and V was at risk of going into care. It became clear that this had been the main problem all along, with faeces soiling many places, concentrated around the bathroom but liable to be found anywhere in the unit. V’s daughter-in-law thought that V was not cleaning herself properly, partly because
of poor eyesight and also because she insisted on using only one-ply toilet paper to save money. She would then wipe her fingers on any available surface. We introduced large toilet paper sheets but this strategy failed because the sheets blocked the septic tank and V became confused by having to put them in a rubbish bin. It was only when V felt sufficiently comfortable to be able to discuss her toileting problems with us (on our fourth visit), that we discovered she was embarrassed when faeces soiled the side of the toilet bowl, and at the thought of her daughter-in-law having to clean it up. (There was minimal water for flushing). Accordingly, V tried to clean it but poor eyesight and motor clumsiness meant that the faeces were liberally daubed around the unit. We used the method of spaced retrieval and fading cues to teach V to associate two concepts:

Q: Why must you leave the toilet bowl for (daughter-in-law’s name);  
A: Because if I do it the pooh (V’s term) gets everywhere and (daughter-in-law) would rather clean it up.

At three month follow-up there had been no incontinence episodes, and no faecal soiling for 7 weeks. V was taking anti-depressants and her mood had lifted, though she remained in the clinical range on the Leeds Depression Scale (see Table 1). She was not using any incontinence pads and her daughter-in-law was not having to do any laundry for V. A further major feature of this case was being able to put the family into contact with support services and also provide basic information about dementia. They had known nothing up to that point. On our follow-up visit, V was about to try respite.

Case 5
D was a 76 year old woman with progressive super-nuclear palsy living alone in the community. She was referred by a home-care worker, who kept finding items of soiled underwear hidden away. D was adamant that she did not want her sons to know that she was incontinent, so we were unable to obtain informant report. She had high pre-morbid IQ and obtained perfect scores on the Abbreviated Mental Test and clock drawing. On the Clinical Dementia Rating she fell into the ‘questionable’ range, which is roughly synonymous with mild cognitive impairment (MCI). She was just within the clinical range on the Leeds Depression Scale. D had insight into her problems, and was embarrassed by incontinence but appeared to have given up,
feeling that nothing could be done about it because of her progressive neuronal disorder. She described the problem as mainly not being able to get to the toilet on time, though she also reported that she had urinary tract infections (UTI) several times a year when the incontinence was uncontrollable. She appeared frail and moved very slowly but was otherwise in fair health.

D was able to do her own monitoring and, over a 7 day period, reported ten episodes of incontinence, 8 where her pads were damp and 2 where they were soaked. She did not have a UTI during this period.

The GP was unaware of the problem because D regarded incontinence as a shameful secret. We persuaded her to let us ask the GP for a referral to a geriatrician for a thorough physical work-up. The geriatrician advised D to reduce intake of tea, particularly in the evening when problems were worst, increase fibre in the diet to reduce constipation, and referred her for an assessment for pelvic floor exercises. We also advised her to go to the toilet at regular intervals whether she felt she needed to or not, and offered her an auditory alarm to remind her. V refused the alarm and did not take up the pelvic floor exercises but accepted the other advice.

At follow-up, three months later, V reported that the main effect of the intervention had been to make her do something about the problem instead of feeling it was an inevitable part of her neurological condition. She was going at regular intervals to the toilet whether she felt she needed to or not. She reported that she was now dry, except for when she had a UTI. She had learned to recognise the symptoms of a UTI, and took a course of antibiotics if she had repeat prescriptions, or obtained a new scrip. She had also realised that she could afford to be looked after and was paying a private organisation to provide companionship and nursing care. Her mood had improved. We had no way of checking whether her claims to be dry except when she had a UTI were true but, given her frankness when we first approached her in discussing a problem about which she had previously been very secretive, we are inclined to believe her. Certainly, home care workers were no longer finding soiled linen hidden away.
Case 6

Y was an 88 year old woman living alone and supported by her daughter who lived nearby. She scored 8 on the Abbreviated Mental Test, obtained a perfect score on clock drawing and fell in the mild range on the Clinical Dementia Rating. She had excellent insight into both her memory problems and her incontinence. Y was reported to be in ‘fair’ health but, a tiny delicate woman, she was extremely prone to infections and hypersensitive to any medication, suffering severe side effects. She had been deteriorating physically for about 6 months and on some days she would have extremely low energy and not get up at all. She was not in the clinical range on the Leeds Depression Scale. Because of her low energy and frequent desire to stay in bed, we gave her an additional mental health work-up and concluded that she was not clinically depressed.

It was not clear how long Y had suffered from incontinence but it was at least a year. We had to estimate frequency of episodes again by proxy; that is, damp or soaked pads or undergarments. During the first week of monitoring there were no incidents, in the second there were 4, mostly in bed. Y reported being depressed and embarrassed by being incontinent. She felt that the main problem was inability to reach the toilet on time, though our monitoring revealed that two soaking incidents occurred on days she spent in bed.

Y was taught using the methods of spaced retrieval and fading cues to associate going to the toilet with an auditory alarm. She readily learned to get up when it sounded and could tell us that she had to go to the toilet but it proved impossible in that first session for her to put it into action. She would head purposefully off in the correct direction but would then lose track and just wander around. Her daughter was given a series of additional cues to use to train Y to remember where she was going, in readiness for a follow-up visit. It is not known whether this would have been possible because Y’s daughter, very protective of her mother, withdrew her from the project at this stage.

Case 7
M was an 89 year old woman living in an aged care hostel. She scored 8 on the Abbreviated Mental Test, and 7 on clock drawing. She presented on the Clinical Dementia Rating as having ‘questionable dementia’ or mild cognitive impairment. She was not depressed but was extremely distressed by her urinary incontinence, reporting a high level of embarrassment and inconvenience. In particular it affected her ability to socialise. Her account of the problem suggested that she was not getting signals early enough to go to the toilet on time. She only wore pads when going out of the building but otherwise insisted on washing her own underwear. She started keeping a record and was washing more than 10 pairs of underwear daily.

M suffered from cardio-vascular disease, and had had a few emergency admissions for suspected heart attacks. For this reason her GP had prescribed a long-term regime of diuretics, including a particularly aggressive fast-acting type. Independent advice was obtained that this medication would significantly exacerbate incontinence. We attempted to persuade the GP to review this but she refused. M did not want to upset her GP and we were unable to get round this problem and obtain a review to determine whether an alternative medication regime was possible.

In the meantime, an attempt was made to train M to use a beeper to help remind her to go to the toilet every 45 minutes. Monitoring of accidents showed that if she waited more than an hour between toilet visits there would almost always be an episode of incontinence. Because of the low staff numbers in hostels, it was not possible to get nursing staff to reset the beeper after each toilet visit and M was too impaired to learn to set it herself. In fact she became confused and irritated by the beeper and, because of this, refused further help with the problem. Fortunately, despite in effect sacking the project clinicians, M did internalise the concept of regular and frequent toilet visits to pre-empt accidents. At one week follow-up, the last time we were permitted to visit, it was clear that there had been no incidents because she had not had to wash any soiled underwear. That is, she was managing to remember herself and did not need the beeper. This case is similar to Case 5, where there was also mild cognitive impairment. The intervention made M realise that she could do something to pre-empt accidents, and she retained sufficient cognitive capacity to self-prompt visits to the toilet, a situation which, according to staff report, continued for some months after our involvement.
Case 8

J was a 74 year old man living in a hostel. He obtained a perfect score on both the Abbreviated Mental Test and clock drawing. He was classified on the Clinical Dementia Rating as showing mild cognitive impairment. J reported that he had been incontinent in the day but that this never occurred now. There were occasional incidents of incontinence at night. Though he had been slightly distressed by incontinence when it first occurred, he no longer regarded it as a problem since he had started wearing pads and since he had also discovered that, as a veteran, the pads were paid for by the Department of Veteran’s Affairs. Analysis of the problem suggested that the night-time incontinence occurred primarily because he went to bed at 8.0 pm and woke around 4.0 am, having had a normal full nights sleep, and with a full bladder. This is the norm for all age groups. He had developed the habit of going to bed early over many years but, previously, had got up to go to the toilet. He now preferred to lie in bed and urinate into a bottle. Sometimes he dozed off before doing so and was incontinent in bed; sometimes his aim was simply inaccurate.

The most likely hypothesis is that J agreed to take part in the project because life in the hostel was somewhat boring. A man with a high status professional career earlier in life, he was not gregarious and spent most of his time in his room, and clearly enjoyed talking to us. However, he was not particularly motivated to deal with the incontinence which, in any case, was not serious. Accordingly, we offered him help should he later become motivated to deal with the problem, and withdrew.

Table 1 overleaf summarises the results of the eight cases we worked on.

*
<table>
<thead>
<tr>
<th>Table 1. Summary of cases</th>
<th>Baseline</th>
<th>Post-intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1: Female, 86, Alzheimer’s disease, mild</strong></td>
<td>5.43</td>
<td>0</td>
</tr>
<tr>
<td>Frequency episodes per week</td>
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<td>3</td>
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<tr>
<td>Pads used weekly</td>
<td>5</td>
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</tr>
<tr>
<td>Incontinence laundry loads weekly</td>
<td>7</td>
<td>4</td>
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<tr>
<td>Leeds Depression</td>
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<td>1</td>
</tr>
<tr>
<td>QOL due incontinence*</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>2: Female, 71, fronto-temporal dementia, moderate</strong></td>
<td>2.4</td>
<td>0</td>
</tr>
<tr>
<td>Frequency episodes per week</td>
<td>14</td>
<td>10</td>
</tr>
<tr>
<td>Pads used weekly</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Incontinence laundry loads weekly</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Leeds Depression</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>QOL due incontinence*</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td><strong>3: Female, 84, ‘dementia’, mild-to moderate</strong></td>
<td>3-4</td>
<td>Case aborted</td>
</tr>
<tr>
<td>Frequency episodes per week</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>QOL due incontinence*</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>4: Female, 74, mixed dementia, mild</strong></td>
<td>2 urinary, faecal daily</td>
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</tr>
<tr>
<td>Frequency episodes per week</td>
<td>10</td>
<td>0</td>
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<tr>
<td>Pads used weekly</td>
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<td>0</td>
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<tr>
<td>Incontinence laundry loads weekly</td>
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<td>12</td>
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<tr>
<td>Leeds Depression</td>
<td>6</td>
<td>4</td>
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<tr>
<td>QOL due incontinence*</td>
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<td>2</td>
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<td><strong>5: Female, 76, Progressive Super-nuclear Palsy, MCI</strong></td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td>Frequency episodes per week</td>
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<td>4</td>
</tr>
<tr>
<td>Leeds Depression</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>QOL due incontinence*</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td><strong>6: Female, 88, vascular dementia, mild</strong></td>
<td>2</td>
<td>Case aborted</td>
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<tr>
<td>Frequency episodes per week</td>
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<td></td>
</tr>
<tr>
<td>Pads used weekly</td>
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<td></td>
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<tr>
<td>Incontinence laundry loads weekly</td>
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</tr>
<tr>
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</tr>
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<td><strong>7: Female, 89, Mild Cognitive Impairment</strong></td>
<td>10+</td>
<td>Refused follow-up, but problem resolved</td>
</tr>
<tr>
<td>Frequency episodes per day</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Leeds depression</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>QOL due incontinence*</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td><strong>8: Male, 74, Mild Cognitive Impairment</strong></td>
<td>&lt;1</td>
<td>Case aborted</td>
</tr>
<tr>
<td>Frequency episodes per day</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leeds depression</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>QOL due incontinence*</td>
<td>3</td>
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</tbody>
</table>

*Quality of life in incontinence scale (higher scores denote poorer quality of life)
Discussion: Comment on cases

The initial aim of this project was to teach older people to associate cues with going to the toilet, where their incontinence was due at least in part to cognitive impairment. It was assumed that a common cause of incontinence is failure to remember to go regularly when the sphincter muscles are not sending sufficiently strong messages until it is too late, and/or difficulty finding the toilet. A learning technique, already applied by the first author from the memory laboratory to other clinical situations, was expected to be the main intervention. In particular, it was hoped that reporting application of the methods of spaced retrieval and fading cues to a specific clinical and debilitating problem, might tempt more cognitive researchers out of the laboratory to try and apply their skills to real-life problems, and also increase the techniques available to incontinence advisers.

There were major difficulties in recruitment and only eight cases were undertaken but this limited number was sufficient to show that incontinence where there is cognitive impairment is more complex than we expected. The proposed learning technique was the primary intervention in only one completed case, though it was used as an adjunct in another. The small sample size and the nature of the complexity changed the focus of the project and this report, accordingly, has focussed on the clinical detail of the eight cases instead of the wider agenda.

The cases themselves do merit comment. They were very rich clinically, with an interactive complex of causality, personal and inter-personal dynamics of the situation, and cognitive and psychosocial resources available. They therefore required a range of psychosocial interventions. Secondly, some cases showed inadequate assessment prior to our involvement even when continence advisors were involved. The most obvious example is Case 2, which was referred to us by a continence advisor. The cause of the incontinence, at least initially, was excessive drinking of liquid with a strong enuretic effect, and the solution was basic advice about fluid intake, as well as helping the husband operationalise this. Other cases showed that continence advisers in our area had little understanding of the effects of cognitive impairment, in particular expecting people with dementia to learn and remember how to do, and then actually to remember to undertake, regular pelvic floor exercises.
Case 1 is a perfect example of the intervention technique as planned but it is the only one, though Cases 3 and 6 might have been suitable. Case 4 was resolved mainly by low-level psychotherapy, including motivating the patient to take continence seriously and helping reduce embarrassment about her daughter-in-law clearing up after her. Case 5 was also resolved by helping the patient move from denial/helplessness to dealing actively with the problem. Despite the intervention team being effectively sacked, and the GP’s refusal to consider a medication review, Case 7 was effective because the patient internalised the concept of regular frequent toileting.

In several cases there were collateral benefits of our involvement including financial savings (reduction in use of pads or external laundry services), convenience (less washing), and providing advice about government-supported linen services for incontinence. In these cases, there were also reductions in depression and improvements in quality of life. In Cases 2, 4, and 5, we were instrumental in providing basic information to carers who, hitherto, had understood little about dementia and had not been put in contact with services until we came. In Case 4 we were directly instrumental in preventing the participant going into care.

Each case took at least three visits by one or both authors to resolve and one (Case 4) took five visits. It was usually not until at least the second visit that we felt we had an understanding of the causes of the problem, and what might be possible given the constraints and possibilities of the individual case-profile. A single consultation may not be enough for clinicians determined to make a difference. However, if there are cost savings as well as personal benefits including delaying institutionalisation, this is a small price to pay.

**Recommendations and conclusion**

No concrete recommendations can be made; it is impossible to generalise from such a small sample. Only two cases required specific expertise in the intervention which was expected to predominate when we planned this project, namely teaching new information to people with significant cognitive impairment, using the methods of spaced retrieval and fading cues.
This pilot study does, however, suggest that incontinence can cause the same distress - including shame and depression - to people with cognitive impairment as it does to people who are unimpaired. It is of concern that there had previously been inadequate assessment, and impractical advice (in particular remembering to do pelvic floor exercises) for people with significant cognitive impairment even where continence advisors were involved. It is also of concern that it was possible to make a major change in two cases simply by low-level counselling to dispel a sense of hopelessness. These factors, coupled with the clinical richness of these cases, might suggest that a more flexible, multi-facetted, and case-specific approach should be adopted by continence advisers asked to intervene where there is cognitive impairment. However, we do not know how typical our experience was of services elsewhere in Australia.

It is difficult to determine why we had so much difficulty obtaining cases for this study. Only one subject had consciously hidden the problem and, though most were embarrassed, subjects were able to talk openly about it after rapport was established. Whatever the reason, our recruitment problems are a cause for regret, given the good outcomes we produced when we were able to undertake and complete interventions. All the cases we were able to complete (five out of eight) had successful outcomes in reducing incontinence and, in most, there were improvements in quality of life scores, depression scores, and use of pads or time spent on washing. Incorporating the 3 cases which had to be aborted into the sample gives a success rate of 62%. It is impossible to determine whether we could have succeeded where cases were aborted; we were hopeful in two of them, but it is more parsimonious to record them as failures.

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References


