BETTER FOR EVERYONE

01 Manager's Toolkit

An Australian Government Initiative

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Welcome to the Better for Everyone Toolkit!

This Toolkit is the product of a project carried out over two years by HammondCare and Uniting Aged Care Victoria and Tasmania as part of the Federal Government's *Encouraging Better Practice in Aged Care (EBPAC)* program. The purpose of the project was to demonstrate that we could *reduce* behaviours of concern of residents by making simple, evidence-based changes in four different areas of aged care.

A large number of people in aged care experience *behaviours of concern, also known as challenging behaviours or behavioural and psychological symptoms of dementia*.

A systematic assessment of these problems in Australian aged care revealed that 52.9% of residents with dementia showed disturbances of activity, 76.5 % showed aggression and 82.2% were behaviourally disturbed[1]. The investigation also showed that these behaviours were not only found in people with dementia: 71.9% of residents who had no diagnosis of dementia were also behaviourally disturbed. The study concluded that behavioural problems are everywhere in aged care.

While we focussed on residents with dementia, (who make up between 70% and 80% of the residential aged care population) we also included some residents with primarily psychiatric diagnoses or developmental disability, and a few frail aged residents.
The approach and techniques described are applicable to all your residents.

In this project behaviours of concern were defined as behaviours that cause concern and/or distress to residents themselves, other residents, staff and/or families. These were not limited to so-called *active* behaviours such as aggression, but also included the *negative* behaviours of depression - apathy and withdrawal.

When faced with distressing behaviour of a resident in a facility, it is easy to react as though the resident and the behaviour are one and the same. However, research shows that much of this behaviour is a **reaction** to the physical environment or to things happening around the resident, and is also a **form of communication**.

Depending on the resident's level of dementia, staff can consider different approaches to personal care which may reduce distress.

Behaviour as communication

By considering behaviour in this light, staff are able to make better choices in responding, behave in a more understanding manner and suffer less distress. This in turn improves the morale in a facility and reduces staff burnout and potentially turnover. In short, greater understanding is better not only for the person receiving care, but for the staff as well.

Improving the physical environment, staff training and the involvement of families can make the life of both residents and staff in facilities better. In this project we added a fourth component: the involvement of an experienced nurse Mentor. The mentor gave staff a 'safe' and experienced person to work through issues they face in their interactions with residents, using a technique of *guided discovery* pioneered by nurses at Lund University in Sweden.

Seven facilities participated in this project, implementing the changes you will read about in this Toolkit. The results were very positive for staff, residents and their families.

The changes in the levels of *behaviours of concern* of 54 residents in three Victorian and four NSW facilities were assessed six times over 12 months of interventions, by an independent team of researchers based in the University of New South Wales. The results showed a steady decline in agitation as measured by the Cohen Mansfield Agitation Index (CMAI), a similarly steady decline in psychiatric symptoms as measured by the Neuro Psychiatric Index (NPI) and a reduction in depression, measured three times with the Cornell Depression Rating Scale (CDRS). These changes were statistically significant and noticeable to the staff and families.

There is little point undertaking research if it remains on a bookshelf or in a computer somewhere and never sees the light of day! Because this study showed how changes, both small and large, can have enormous and positive effects not only for residents but for staff as well, we have put together this Toolkit for use in other facilities. In it you will find information about the original research program as well as the assessment and evaluation tools and training materials needed to apply what we learned to your own facility.

Each of the four components of the project is covered by a section of this Toolkit: staff training, the Mentoring program, family support, and design of the physical environment, along with an explanation of how we evaluated the project.

The Toolkit has been broken into sections for different people. The first and largest section is written for people with decision making roles within the facility, whether they are the facility manager, the director of nursing, finance or management decision makers in a corporate office. The bulk of the information and the tools are in this section. This section is complemented by the sections for staff and families which focus on the needs and actions that we found were most important during our project. While these two resources can be used independently, the best results will arise when they are used in conjunction with the first part of the kit.

The evidence

There are a great many people in Australian facilities whose behaviour causes concern to the staff, their families, their fellow residents and themselves. We know how to substantially and significantly reduce these behaviours and the interventions are very straightforward.

Our project found that:

- A reduction in *behaviours of concern* can be brought about by modifying the physical and psycho-social environments, suggesting that the roots of the behavioural problems are environmental and not lodged in the personality of the resident or the diseases that they may have.
- The physical environment can be improved by the systematic application of existing knowledge. Tools already exist that can greatly assist staff to do this, and one is included in this Toolkit.
- The right staff training can provide a basis for learning and assisting staff to grow. However, when they are provided with an ongoing, safe psychological environment in which to explore their feelings and problem solve, their knowledge is extended and can be acted upon.

- Regular Mentoring sessions are valued by staff and contribute to cohesive teamwork, improved understanding and overall reduction of *behaviours of concern*. The Toolkit provides a guide on how to Mentor for those who have the skills, the time and the opportunity to separate themselves from managerial responsibilities and establish a safe place for staff to discuss and be heard. Where no such person is available, we recommend that time be put aside so that someone with potential can be provided with training and opportunity to become a Mentor. If your facility is part of a larger organisation, it is worth enquiring whether there is a person who works across sites in a similar capacity as a leader, Mentor or resource.
- While the involvement of family members can be very helpful for both staff and residents (as well as for them dealing with the changes their loved one is undergoing), families are often unwilling to get involved in the 'life' of facilities and it is sometimes difficult to find ways of meeting their expectations. Some staff feel unable to manage more than superficial interaction with families.
- A support group for those families who wish to explore their roles and concerns is described in the tool kit. It is designed to be used as an extension of the Mentorship program.

The approaches demonstrated in this project were valued by the managers involved and were not seen as an additional burden. However, the success of the project was dependent on the provision of a skilled Mentor. The Better Outcomes section gives more information on the benefits of investing in a Mentor and the potential long term savings created by short term expenditure on the physical environment, good staff training and frequently run family groups.

While we advocate for a Mentor, it may not be possible to adopt this recommendation – or every other part - of this project in your facility. We hope that at least some components will be particularly appropriate and useful to you.

We hope that each section will provide appropriate information and suggestions for the challenges you face, which overall may help you to make life at your facility better for everyone.

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[1] Brodaty, H., Draper, B., Saab, D., Low, L. F., Richards, V., Paton, H., & Lie, D. (2001). Psychosis, depression and behavioural disturbances in Sydney nursing home residents: prevalence and predictors. International journal of geriatric psychiatry, 16(5), 504-512.

Contents

BETTER FOR STAFF

Our experiences

The wellbeing of residents is the most important aim for any facility. The wellbeing of the staff is one of the major factors that affects the wellbeing of residents. The two go together. Central to the training provided in this Toolkit are opportunities for the staff to reflect on how interacting with residents who are living with dementia makes them feel and to better understand their own responses and practices. The training materials in the Toolkit not only consist of information to be presented to staff, but also plenty of information on the subjects of dementia, *behaviours of concern*, teamwork and useful communication strategies.

Responding appropriately to *behaviours of concern* is a complex task. In our project, we found that not only training the staff but also providing a long term Mentoring relationship with an experienced RN provided opportunities to work through residents' behaviour, staff responses to it and ways to respond to or even prevent dangerous, disruptive or distressing behaviours.

More staff education… so what?

A common management response to improve care and staff attitudes has been the provision of staff education. Teaching sessions alone are unlikely to change practice, but interactive workshops can be an effective means of achieving long term changes in knowledge, skills and attitudes.

Our project began with two days of staff education, (aiming to include at least 80% of the staff caring for the residents who were part of the project), and an environmental audit which is described under Better Design. An assessment of the knowledge of the 171 staff attending showed that it improved significantly over the course of the training. The attendees had, on average, 9.71 years of experience of working with people with dementia and almost one third of them had a tertiary qualification; so the training added something to the knowledge base of experienced and qualified staff as well as to relative newcomers. It also made a significant difference to those with much less experience and those with literacy problems.

Training plus Mentoring

While the transfer of specific knowledge was important, the main purpose of the training was to introduce the mentor, establish her as a subject matter expert and to lay the foundation for productive mentoring sessions which would continue for the next 12 months. The training sessions also established a common language for staff when it came to discussing *behaviours of concern*.

The training provided an opportunity for the staff to get to know the person who was about to become their Mentor and who would work with them for 12 months on a journey of *guided discovery*. This would be a process where the Mentor would use questioning techniques aimed at helping the staff to discover information about residents for themselves to gain a better level of understanding of the resident, their *behaviours of concern* and the staff members' own reactions.

Following the training the Mentors met every two weeks for up to an hour, with the staff involved in the care of residents identified with *behaviours of concern*. The meetings were aimed at helping staff understand their own feelings, the feelings of the people with *behaviours of concern* and how they could use an understanding of these feelings to work in a different way to reduce the *behaviours of concern*. This was achieved by the Mentors establishing a safe psychological environment in which the staff could talk about events such as being spat at, hit or called hurtful names. For many staff this opportunity to share and be heard was a totally new experience.

Prior to mentoring sessions

1. Schedule fortnightly sessions.
2. Identify a resident who requires help one week prior to session.
3. Familiarise yourself with his or her history and problems.
4. Identify a staff member who will contact family and research her background.

The Mentors also guided staff in considering alternative ways of understanding and responding to the behaviours using a problem solving strategy pioneered by nursing researchers at Sweden's Lund University.

The Mentoring was received very well by the staff in every facility. Almost all staff wanted the Mentoring support to continue after the conclusion of the project. An objective measure of staff strain showed an improvement in understanding, and empathy and a significant reduction in the frequency of staff feeling that they did not understand the needs of the resident.

Challenges

There were difficulties in some facilities in finding a private space, conducive to sharing feelings and experiences. In one facility sessions were conducted from time to time an unoccupied bedroom in areas that could potentially be overheard, or in treatment rooms that were interrupted as other staff attended to their duties. Staff would be called away from time to time to attend to issues as they arose.

Maintenance of staffing levels during mentoring, across all facilities remained an issue throughout the project. Having some staff absent on planned (e.g. annual leave) or unplanned leave (e.g. sudden illness) created significant burdens for staff on the floor if replacement staff could not be found. Likewise when emergency situations occurred, staff were unavailable to attend sessions at the planned time. In these cases, Mentors were flexible, and would often work alongside staff, practically reinforcing the strategies developed during Mentoring sessions and honing clinical skills and techniques. This had the effect of increasing positive staff attitudes about the Mentors.

Although all facility managers agreed that collaborative case conferences (with and without families) were best practice, initial acceptance of the Mentor and support for the Mentoring sessions varied. In the worst cases at the beginning of the project, the sessions were barely tolerated by the manager: the Mentor had to walk through the facility and encourage the selected staff to attend. In the best cases, the managers planned rosters to enable the greatest number of staff to attend. By the end of the project all the facilities agreed that the Mentoring was useful and highly desirable for better understanding of, and care planning for residents. Mentors no longer had to go and find staff, but arrived to find staff prepared and eager for the session to commence.

Sustainability of the training and mentoring process

During the project we sought to identify staff from each facility who would continue the Mentoring. We identified three criteria for potential Mentors:

1. Required skills and attitudes (described in the job description on page 15).
2. Time to undertake the role
3. Distance from the day to day responsibilities and decision making enabling staff members to see the Mentors as a safe, neutral person able to hear their concerns without having to act. For example, a staff member should feel able to say *'I feel totally inadequate – I don't know what I'm doing'* without worrying that they are considered inappropriate to do their job.

The staff need to be free to offload emotional statements like these to a Mentor, in order to get things off their chest.

Staff who appear to have these attributes or the capacity to develop them should be cultivated as possible future Mentors or as *workplace Champions*.

Using a Mentoring process in a safe psychological environment will improve care responses but can also ultimately change cultures and create learning organisations. An added benefit discovered as the project progressed was that because staff felt safe to speak up about issues or concerns, we were able to spot potentially harmful and costly problems, avoid incidents and manage family situations before they became complaints.

Unfortunately, we were unable to identify staff who could be developed into Mentors. Without Mentors embedded in the facility, there is no assurance that the gains made will be maintained.

Dealing with negative information revealed in Mentoring sessions

1. Agree with the manager on a protocol for dealing with negative reports. The protocol must allow the Mentor to be trusted by the staff and should only require the Mentor to make an official report in the case of a serious breach of conduct.
2. Ensure that all staff attending the sessions are aware of the protocol.

The sustainability of this project rested on finding a way to encourage organisations to use available funding to employ someone in the Mentorship role. We hope that the demonstration of the reduction of *behaviours of concern* provided by this project and that the free availability of this Toolkit will enable you to trial and assess a Mentoring program in your facility.

Lessons learnt

The initial problems with finding appropriate settings and times for the Mentoring sessions and getting staff to attend were solved by the Mentors working alongside the staff. This built rapport and provided caluable modelling of skills.

The most effective way of maximising support for positive change is to have a *Champion* of the project within the facility. The *Champion* should be a senior staff member who can arrange the sessions, give permission for staff to attend may sometimes attend herself. It is even better if staff cover can be arranged whilst the sessions are in progress.

Informal contact with staff at different times was used to communicate what had happened during sessions to those who had been unable to attend. In each case staff input to the care plan was noted and staff were encouraged to briefly discuss any problems they had. A flexible approach paid dividends.

Over time, as staff came to see the value of the intervention, attendance became more consistent, often with a small core group of staff, some of whom came even on their days off.

Training materials

The training materials in this section have been developed from those used in the project. They have been updated and adapted to give plenty of background information, support and suggestions for good delivery for your trainer.

The materials were originally based on the HammondCare *Dementia Care Essentials Program*, but were reviewed by the team to ensure that they could be used to deliver a basic understanding of dementia and the complexities of behaviour. The training is intended as a starting point, enriched by ongoing input from the Mentor.

The training materials include:

- Training Powerpoint Presentation
- Student Workbook
- Trainer Manual corresponding with the material in the Presentation and Workbook

The content is made up of the following modules:

- Introduction to the project
- Introduction to the Lund philosophy
- Understanding *behaviours of concern*
- The three “Ds” of aged care: Dementia, Delirium and Depression
- An introduction to effective communication
- Relating effectively to families
- The environment
- Enabling activities
- Case conferencing
- Telling the resident’s story

Substantial additional reading material is included in the Student Workbook to enable those who are interested to go into the subjects in greater depth.

The staff resource booklet *Better Understanding* is designed to add to the training, not replace it.

General background to behaviours of concern

What research tells us

Behaviours of concern in aged care include a wide range of examples such as resistance to personal care and other aggressive responses, repetitive questions, yelling or screaming, sexual disinhibition, and apathy. By definition, they cause significant distress and treatment is problematic. There is extensive evidence of over-reliance on psychotropic medication, (in particular anti-psychotics) to manage behaviour, despite all research since 1990[2] showing at best, modest efficacy and undesirable side effects. As a result there are frequent recommendations to make psychosocial interventions the first line of treatment. **But which interventions and for which behaviour?** A problem with this way of thinking is that it assumes that the same intervention applies to all similar behaviour. This encourages us to view the person as the patient and the behaviour as the symptom to be treated. This approach could be characterised as the search for a *silver bullet solution*, the one shot which will fix everything.

The Original Lund study

The earliest and most comprehensive project covering both staff and resident emotional, physical and practical needs was undertaken at Lund University in Southern Sweden. This study was carried out in the context of caring for people with dementia. The principles underpinning the approach are applicable to staff and residents in general:

1. People with advanced dementia are often totally dependent in all aspects of care, including highly intimate and even invasive tasks that we take for granted until we ourselves are helpless.
2. Staff observation showed apparent lack of care, callousness or coercion, in tasks like bathing, toileting and feeding, concentrating on just getting the job completed.
3. Investigation showed that staff did care and knew that residents were suffering.
4. The problem was staff not knowing how to communicate with residents or understand their individual physical and emotional needs, which increases the pressure to withdraw into task-oriented care.

The problem with looking for a silver bullet solution

Unfortunately, the problem with standard treatments is that they largely ignore the fact that cause and effect can be complex. There are usually multiple factors underlying the behaviour and, equally, multiple factors causing the behaviour to be perceived as *challenging* by care staff. For example, some of the causes of nightly disturbances include: staff waking residents up; residents sleeping/dozing or being inactive during the day; being unable to find the toilet or the way back to bed at night; the person’s night-time habits before they were diagnosed; or any combination of these.

Equally diverse factors can contribute to vocal disruption in dementia (e.g. screaming, moaning or repetitive calling out; or questioning), including pain or under-stimulation, over-stimulation, anxiety, the nature of social interaction with care staff, or post traumatic stress disorder. Different reasons apply equally to distress amongst staff, whose emotional response to the behaviour varies widely and is often determined by factors other than the person with dementia or the behaviour.

These factors include lack of staff support, limited understanding of dementia, and unpleasant attitudes towards residents.

These examples illustrate that there is no single, simple solution for these problems. Every case is different. They also illustrate the complex relationship between the behaviour of the person with dementia, the physical environment, staff behaviour, attitudes and emotions.

This relationship, which is constantly evolving, has the potential to produce both positive and negative effects for staff and resident well-being.

Key points

1. There is no silver bullet answer for these behaviours, whether pharmacological or psychosocial, because every case is different.
2. In residential care, staff and residents are in a continuously evolving dynamic relationship; what staff do and feel affects the behaviour and feelings of residents, which in turn affects staff, and so on.
3. The Lund approach attempts to intervene in this circular relationship to maximize quality of life for people with dementia and, by extension, those providing the care.

The original Lund study on caring for people with dementia

What did they find?

A key finding was the problem of communication with residents who could no longer easily make their physical and emotional needs known. This led to the withdrawal by many staff into a task-oriented approach, focusing on physical care – often delivered in a coercive rather than mutually cooperative way with the resident, and the consequent absence of any engagement at an emotional level. Some interactions could be seen as an abuse of power, and their consequences included increased resident dependence, withdrawal or resistance and outbursts of disruptive behaviour.

Why did this happen?

The Lund approach shows that the nurse/resident relationship is critical. The totally dependent circumstances of people with advanced dementia force them into close and often intimate contact with care staff. There is a dynamic relationship between what staff do and feel, and what residents do and feel, including withdrawal and dependence or other *behaviours of concern*. Because the relationship is dynamic, the way facilities are run influences quality of life for both groups.

What did they do?

The intervention devised by Ingalill Hallberg and colleagues[3], the Lund model, was designed to support residential care staff in their emotionally and physically difficult work and, at the same time, increase their ability to understand and meet the individual physical and emotional needs of each person for whom they cared. Staff participating in the project were invited to consider what the resident's world must be like now, as opposed to their life before the onset of dementia:

> *Who is this person really (rather than the nuisance in room 5) and what must life be like for them now, compared with how it was before?*
>
> *What are this person's unmet emotional physical, medical or social, needs? Might they, or elements of the environment be contributing to the behaviour?*

From this process, care plans would be developed based on each resident's individual emotional and physical needs rather than the problems they presented. **They were genuine care plans rather than management plans**.

A particular feature of the approach in both the fortnightly clinical supervision sessions and the weekly nursing care forums was *guided discovery.* Although Hallberg and her colleagues had already done detailed research on the resident, and might have clear ideas about his or her needs and how they could be met, the purpose was that the staff become empowered to develop the skills to make these discoveries for themselves, instead of just being told the answers.

Did it work?

On evaluation after one year, there was measureable improvement in care interactions, with less resistance from residents and more cooperation between residents and staff. Nurses showed increased creativity, job satisfaction and less burnout. Residents' orientation and mood improved[4].

Mentors should have sympathy for and understanding of the residential staff and those they care for, including the multiple reasons residents develop behaviours of concern.

Mentors

In the original Lund intervention a senior nurse provided the clinical supervision for two hours every fortnight, and two other RNs worked with staff each week to develop and implement the nursing diagnosis. In the Australian project both roles have been undertaken by a single nurse educator (the Mentor), who was available on site for up to seven hours per fortnight.

The Mentor's role was to establish a safe psychological environment for staff to explore their feelings about the care they provide and to discover new ways to approach people whose behaviour causes concern.

Mentors should be experienced in similar work, have sympathy for and understanding of the situation of residential staff and those they care for, and an understanding of dementia, including the multiple physical, medical, social and environmental reasons residents develop behaviours of concern. It is possible to train Mentors with at least some of this background but an essential component is the ability to draw out and build on knowledge from those they are Mentoring (*guided discovery*).

Educators who favour an instructive, classroom only approach cannot do this work; it does not suit adult learning, which must be grounded in linking new information to what is already understood. Though there are some common causes of behaviours of concern such as pain, or residents misinterpreting what is happening in intimate personal care, in practice each case is unique. It is the Mentor's job to help staff themselves develop the skills to understand the individual and collective causes of distress in each resident. This enables the staff to better understand the nature and causes of their own response to the resident and to make adjustments or undertake interventions which will improve quality of care. These adjustments and interventions can also be effective in increasing the quality of life for both residents and staff.

It is essential that Mentors receive peer support. The job description we used for our Mentors is included in this resource.

NB: These guidelines are based on the experience of the authors in adapting these principles in Australian residential care.

The Mentoring process

In the Australian project, 'Lund sessions' were provided fortnightly. Fortnightly meetings allow a complete review of the care of 25 residents a year. The choice of which residents to review is based on the degree of distress of staff, the severity of resident need and the time it takes to get to know newly admitted residents. Sessions normally take place around hand-over time, when two overlapping shifts are on the premises. In our experience, unless the facility is really efficient or so committed to the project that they provide cover for participating staff, the longest period Mentors can hope to have the group together is 30 minutes.

As in the original Lund study, it takes time for staff to feel comfortable about discussing emotional engagement with residents. However, if the Mentor has managed to establish rapport and staff see her as a support, most will become comfortable. The Mentor needs to create a safe psychological environment where staff can be sure that disclosures will be treated confidentially and with respect.

Before Mentoring can begin, it is necessary to:

1. Explain the approach, and the evidence for it, to senior managers.
2. Obtain agreement to introduce it via the provision of the two day training course.
3. Agree on frequency and timing of sessions with relevant managers.
4. Provide training and introduce the Mentoring program.

Content of the sessions

The resident to be discussed was selected beforehand. Before the session, usually in the previous week, the Mentor familiarised herself with the physical, emotional, and behavioural profile of the resident, and her interactions with staff.

Before the session a staff member was also either selected or volunteered to research the background and history of the resident scheduled for discussion. This included contacting the family to try and answer the question: *Who is this person*?

In some cases the Mentor initially had to provide significant support for staff to carry out this process. It is worth doing this at the start to show how to obtain background information, which will not only make the resident come alive as a person but also, hopefully, increase staff empathy, and give clues on where the behaviour may be coming from or strategies that can be tried.

During the group supervision sessions, a staff member presented the resident's social and health history. Discussion was encouraged to consider the implications of this history on current needs, behaviour, and care. Staff observations of the resident's physical and emotional state, and their intimate day to day knowledge of the resident completed the picture. Importantly, members of the group were also encouraged to discuss their feelings about the resident.

Eight hints for Mentoring sessions:

1. Support and encourage the staff member as she presents the information she has gained from her research.
2. Encourage her to talk about how she feels when she is looking after the resident.
3. Encourage others to talk about their feelings.
4. Encourage staff to look at the situation from the point of view of the resident.
5. Encourage reflection on how the behaviours of concern are being responded to.
6. Encourage the exploration of new ways to respond.
7. Agree on a new approach.
8. Ensure the new approach is entered into the care plan.

Staff doing the legwork

It is essential that staff start to undertake this task themselves as soon as possible. In the Australian project, **staff reported that learning more about the person and then sharing it with colleagues was one of the most powerful aspects of the intervention**. They likened it to the kind of information they hear at resident's funerals where they often think: "If only I'd known that when she was alive and we were caring for her". They also reported that it leads to improved relationships with families.

Many facilities have background history in the files, but these are often gathered soon after admission when the family is stressed, and few staff look at the files. Sessions should start with a short presentation by a member of staff using recently gathered information to answer: *Who is this person*?

A practical consequence of this discussion is that when staff hear their work and their concerns placed in this context they can begin to critically reflect on what has happened. With encouragement they can move on to analysing why they feel as they do and what is occurring in the resident's life that is contributing to the events they share.

As one of our Mentors put it, staff move from claiming 'this is the worst resident in the world!" because he is resistive to assistance with hygiene to "no wonder he does that".

Job description: Mentor

Primary Responsibilities

1. The delivery of a two day training course (experience in delivery of adult training and education).
2. The leadership of care planning meetings that will focus on reducing the *behaviours of concern* of 6-8 residents. These meetings will be reflective rather than prescriptive. The Mentor will provide emotional as well clinical support to the staff and encourage them to review their practice, their feelings and their perception of the residents' feelings in the expectation that in doing so new and more effective methods of reducing the *behaviours of concern* will be discovered.
3. The leadership of a relatives' support program that will:
   - **a.** Provide education to the relatives about common reasons for people's *behaviours of concern*
   - **b.** Support the relatives through an exploration of the reasons for the particular behaviours of their family members
   - **c.** Enlist the support of relatives in the development of care plans for the person with *behaviours of concern* and support the relatives while the staff are trying to help the person with *behaviours of concern*.

Essential Experience

1. Hands on delivery of care in an aged care setting
2. Leadership of care planning meetings
3. Specific experience in caring for people with *behaviours of concern*

Essential Qualifications

1. Certificate IV in Assessment and Workplace Training
2. Relevant tertiary level health or aged care qualification

Essential Skills: Ability to

1. Effectively communicate with direct care staff
2. Keep accurate and clear records
3. Establish and maintain a *climate of acceptance* that will assist the introduction of change for all levels of staff in facilities

An introduction to concept mapping

For this project an approach known as *concept mapping* was used by the Mentors as a framework for reflective-learning, problem-solving and the care planning process. *Concept mapping* provides an efficient visual framework for reviewing and documenting what is known about the person, and then using the data in problem-solving.

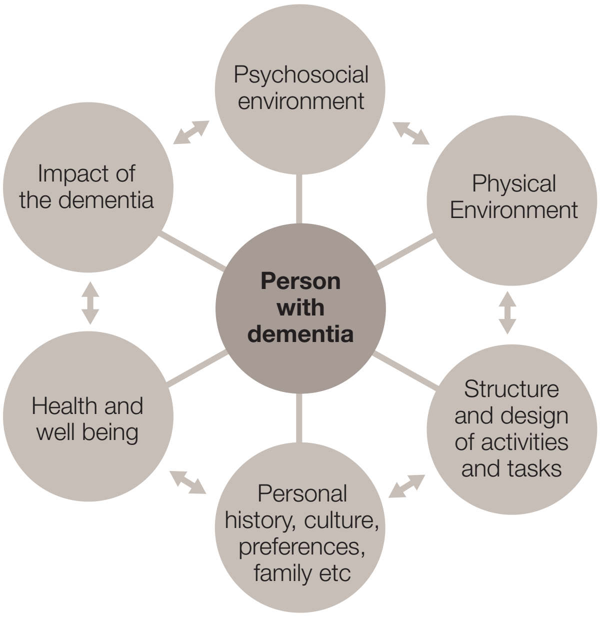
How concept mapping works

Concept maps have various forms such as flow charts and *chain of command* maps. We used a spider-web map in which the **person** rather than the **behaviour** is the central concept and personal strengths as well as problems are documented. The emphasis in *spider-web concept mapping* is on critical reflection of any assessment data, uncovering the facts and finding relationships between them. The map itself is a valuable record of problem-solving, but the process is also of major importance to staff. The process of coming together, of sharing and exploring ideas, reflecting on successes and failures and generating strategies allows staff to address the causes of *behaviours of concern* (as shown on the map) and to learn from the process and each other, as a team. This adds enormously to the value of concept mapping.

In our project, *concept mapping* was conducted as follows:

- The aim was the person-centred care of a person with challenging behaviours. The person must therefore be the central concept, drawn on the white board or butcher's paper.
- Other concepts related to the person were explored:
  - the person's health and general well being; what conditions do they have and what is their impact?
  - the impact of the physical environment; does it enable or disable?
  - the tasks or activities in which the person engages; are they tailored to their abilities (or have we excluded them because we assume that they can't do them)?
  - how well do we and others communicate with the person?
  - their history, preferences, skills, social, cultural, sexual and spiritual identity; and
  - the impact of their health and diagnoses (e.g. of dementia) on cognitive function; what is lost and what is still intact?
- Data was collected from the team, and from existing documentation.
- Discussion and analysis about the assessment data, other documentation and staff experiences of care. Facts were recorded on the map, or where facts were not clear and more information was needed, a question mark was placed to indicate the need for a follow-up inquiry.
- The team reflected on the accuracy and relevance of the data relating to the person and their care, cross-linking relevant concepts to identify *triggers for behaviours of concern* and possible strategies. This involved:
  - observation and analytical reasoning to link cause and effect;
  - the identification of likely triggers and alternative triggers;
  - reflection within the team on the accuracy of the data, relevance to the resident and current care strategies; and
  - agreement on the most likely trigger/s and the framing of a problem statement that describes the behaviour in context.
- Consensus was achieved by the team on cause, effect, helping strategies and potential risk.

An example of a *spider-web* concept map



Care plans: from an accreditation necessity to a living document

In Australia care plans are often formalised documents that do not accurately represent the reality of care provision. They are viewed by staff as useful only for accrediting and funding purposes rather than as a document that tells the story of their care and one which celebrates their thinking and their expertise. The Mentoring sessions provided not only an opportunity to explore and reflect on feelings and experience, but also to encourage staff to collectively learn from their discussion and evaluate and update the care plans. In this way, care plans became truly representative of their care. Successes in care were celebrated and included in the updated plan, failures in care were greeted with understanding and explored and learned from. Staff, sometimes for the first time, had some control over care plan content and consequently felt a sense of ownership. This in turn encouraged them to communicate the plans to other staff who could not attend and to take responsibility for evaluating the success or otherwise of their strategies.

If staff feel safe enough to share feelings and experiences, to contribute suggestions and strategies, they need to be rewarded by knowing that their ideas are taken seriously by their peers and by management and that these ideas are acted on, or that an explanation is given if this is not possible.

Collective reflection, discussion and problem-solving led by knowledgeable and experienced Mentors can reduce the burden on individual staff, capture staff knowledge of the person which otherwise would not make it to the formal documentation, and improve the skills and knowledge of all staff.

Because less time is available in most Australian facilities for this process than was the case in the original Lund study, some communication about the resident and informal teaching or exchange of information happens outside the session while the Mentor is still available on site.

Moving away from the script

As long as most sessions stay on track, it is fine (and sometimes necessary) to be flexible. We experienced supervision sessions where staff needed to discuss a separate issue, such as debriefing after the death of a much loved resident. Other situations are more problematic: for example, in facilities where staff complained about management difficulties or being understaffed, staff used the sessions to ventilate or raise concerns. In our project, the Mentors found themselves in a difficult position. Staff made these disclosures because of the connection that had been established but the Mentor was there by permission of management and it was not her role to become involved in the general management of the facility. Other problems might arise when the Mentor sees questionable care practices, or when staff report perceived malpractice. Peer support sessions for the Mentors were essential to the resolution of these issues.

Inclusion of families in some of the sessions was a positive change from the script. When families wanted to participate their feelings and experiences were valuable for staff to hear and vice versa. Whilst it may seem risky to have frank and meaningful discussion about problems in care that include families, our Mentors reported their experiences as strongly positive for all parties.
The Mentors were, however, experienced communicators and facilitators.

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BETTER FOR FAMILIES

Family support – evidence from research

Many facilities have family support groups. Families – either as a group, one or two members or an individual - are also often closely involved in the process of admitting a resident to a facility and providing the appropriate legal, medical and financial background information.

Despite this, families are often underutilised as an information resource and can feel cut off from their loved one once they have settled into care. What is more, seeing their relative displaying *behaviours of concern* can be immensely distressing for family members already coping with all the emotions that come with the decline of someone they care about. Guilt also often accompanies the process of admission, because the family are no longer able to help keep that person at home.

Having the families of your residents more involved in the life of the facility has many benefits. It will help the families to understand the care their relative is receiving and to learn from other relatives going through experience. It can also provide opportunities for the staff to get to know the resident better, through the memories and insight of family members and it can bring great joy to the residents themselves.

Note: *in some cases there may be a friend or neighbour who acts in the role of a family member, although he or she is not technically a relative. Although we use the word family throughout this resource, this information is relevant for them too.*

Setting up family groups is not easy. Families are busy and often overstretched. Spending extra time at the facility, but not with their loved one, may be the last thing they want to do. That is understandable. Nonetheless, suggestions for how to present this opportunity are given below, as well as what we learned from the project. As an introduction, we have included a summary of research on this subject. This research helped us to plan the family groups for our project and may be helpful for you to think more broadly about what will be of most benefit in your facility.

The involvement of family is universally regarded as best practice in the management of residents who display *behaviours of concern*.[5] The family is an important source of information, including residents' personal history, life experience, beliefs and personal likes and dislikes. The family is essential where the residents' communication skills are impaired and can be an important source of emotional and social support for residents. In conjunction with staff, family are often able to interpret the meaning of behaviours or suggest the unmet needs that behaviour attempts to communicate.[6]

Best practice guidelines suggest that staff and family must work together as 'care-partners' to achieve optimal functioning and quality of life for the resident.[7] However, the three-way relationship that exists between family, residents and staff is complex. Many factors influence the nature and health of these relationships. For the family carer, significant factors include:

- Emotional reactions to placement and witnessing the decline of the family member in care: If there are issues of guilt, fear or other unresolved interpersonal problems within the family, or even particular to one family member, this will have an impact on the way family members interact with staff[8]
- The presence of depression[9]
- Disruption to the family carer's role: Once someone goes into full time aged care, the person who has cared for them in the past must reinterpret their caring role. It can be difficult to go from being the authority and person in charge to being an outsider who needs to ask staff how the resident is;
- Creating uncertainty about where the family carer will *fit* in once a move to aged care has occurred[10] and
- Carer's level of knowledge about dementia: Lack of knowledge of dementia has been associated with the misinterpretation of behaviour. For example, repeated questioning may be interpreted as antagonism toward the family carer, rather than a symptom of memory decline.[11]

Having the families of your residents more involved in the life of the facility has many benefits, including to help the families to understand the care their relative is receiving.

The relationship between the carer and the person being cared for prior to placement in aged care affects the nature of involvement once aged care placement has occurred.[12] Spouses generally want and need more involvement than other family members, while adult children (after initial placement and the development of trust and satisfaction with the care) want less involvement as work and other family commitments again take a greater role in their lives.

There is little research concerning the influence of the relationships before diagnosis on the amount or type of involvement wished for by families. Nonetheless, factors such as a poor marriage, previous psychiatric history or alcoholism - in either partner - can have profound effects on the relationship after residential care placement.

Staff and families have differing perceptions about the physical and psychological needs of cognitively impaired residents. Some families in our project saw themselves as part of the care team and expected to have ongoing connections with staff. However, lack of recognition of family members' expertise led to conflict with staff and family members feeling rejected and *like outsiders*. The role of carer changed from *being the expert to being the visitor.*[13] Relatives can feel left out of decision making. While families may not be critical of what was done, they could be critical about how care was provided. Their expectations of staff demonstrating empathy and kindness while carrying out the required tasks were not always fulfilled.

The role and care relationship changes with entry to a facility, however the stress or burden experienced by carers does not always go away. One study concluded, unsurprisingly, that the *careers of caregivers (family carers) do not stop at the institution's door, but continue in an altered and still stressful way".*[14] In another study of a sample of regular visitors to residents, one-third of all relatives were experiencing significant psychological distress with the greatest distress found among spouses. Although the physical stress of caring may reduce with admission to residential care, the emotional turmoil often continues. Families' experiences of placement of a relative in residential care are characterised by three dominant emotional experiences: relief, guilt and depression:

Relief

Families can feel a sense of relief immediately after placement. Many placements occur around the time the carer can no longer cope and is exhausted. However, for many, once the initial exhaustion lessens this sense of relief gives way to guilt.[15]

Guilt

Guilt can contribute to carers coping less well after placement. Many carers feel that they have failed their relative and these feelings are often intensified if there has been conflict in the family about the placement.[16]

Depression

Numerous studies have demonstrated increased levels of depression in carers, but the picture is complex. In many cases a negative spiral may develop. For example, if the older person being cared for has less recognisable symptoms of dementia, including behavioural, psychological or psychiatric symptoms, the carer is more likely to be depressed and cope less well. *Behaviours of concern* are associated with greater likelihood of seeking residential placement.[17]

Depression is also associated with poor communication between staff and family carers with the family believing that the resident is not adjusting to the placement.[18] This can lead to increased carer stress and depression.

Feelings of depression and guilt of family carers do not disappear after placement. They can be made worse by factors including:

- Limited access to information regarding the disease progression, the resident's changing condition and facility's culture and practices, especially to families of culturally and linguistically diverse backgrounds;[19] and
- Ignorance about symptoms of dementia. For example: common behaviours such as forgetting where items are placed, or hiding items, and expressing this as "someone is stealing my things"; hallucinations or misinterpretations such as "there was someone in my room last night", can be interpreted literally and become a source of distress for the family carer, and as a consequence, a source of distress for care staff.[20]

The poorer the emotional or mental state of the person with dementia was, the poorer the adjustment of the family to placement is likely to be.[21]

On the other hand, successful partnering with families can have positive effects for residents, staff and families. Where staff systematically sought biographical information about residents from families to use as the basis for care planning, this has resulted in benefits including simpler and more obtainable care goals; greater family involvement; reduced medication; and more individualised care. Staff also benefitted from the process, with less burnout and fatigue; improved attitudes toward residents/relatives; and increased job satisfaction.[22]

Four themes which describe the ways in which families would like to be involved are:

1. ***Engaged involvement*** – to reduce their sense of loss of role and find new ways of caring.
2. ***Being valued*** – ensuring that families' specialised knowledge about the resident is used as a basis for care planning.
3. ***Concern*** – not only the process of negotiating boundaries between family carers and the staff, but also ongoing negotiation to explicitly build a productive partnership.
4. ***Continuity*** – the opportunity to remain involved and continue to share a fruitful relationship with the resident.[23]

Support groups are recognised as an excellent way for addressing the emotional, support and information needs of families and become a platform on which caring partnerships are built.[24]

Elements of successful carer support interventions can comprise:

- Psychological support e.g. expression of feelings
- Educational information giving and receiving e.g. information about dementia
- Support system development e.g. encouragement to identify people in social networks who can offer support
- Role reinforcement of the family member in the residential care setting e.g. providing opportunity for appropriate activities for families and resident
- Support for family members in decision making processes, particularly proxy medical and care decision making
- Provision of information about dementia, *behaviours of concern*, the resident's decline over time, nursing home procedures etc; provision of information about normal emotional responses of families to facility placement, and
- Referral to specialist services to treat anxiety, depression when indicated

Both individual and group information and support sessions can benefit families and provide a support network.[25]

There is a growing body of international research that demonstrates that families remain involved or wish to remain involved after placing a relative in a facility. Families often comment on the need for more communication from the staff. Some studies suggest that family members' willingness to assist may not always be recognised.[26]

An emerging theme is that families would like to have more involvement with their relative in quality activities and spend time together including taking their relative out. Poignantly, one researcher quoted a relative who said there was nowhere private to sit in the nursing home - not even on the resident's bed!

Various studies have illustrated the variety of family relationships and models of involvement in the process of caring for a relative living with dementia, as well as the effects of this involvement on the caregivers. Such studies have also shown how improved communication and support could produce positive outcomes for staff, families and the person living with dementia themselves.

The research reviews provided a great deal of support for the development of our project interventions. Because we aimed at reducing *behaviours of concern* in residents of aged care homes overall, we integrated this information into the program of environmental modification, staff education, regular staff support and family involvement.

Starting family support groups- our experiences

Approximately six months after mentoring commenced, families were invited to participate by joining family support groups. Approximately half of the residents had families who expressed an interest in doing this but only half of these took part. Family support groups were run in six of the facilities. In the seventh, no families wished to take part.

The family support groups began as a means of explaining the project, and presented a structured discussion about the aggregated results of the Family *Perceptions of Caregiving Role* (FPCR[27]) scale, (a copy of this scale is provided in this toolkit) which we had used at the beginning of the project to assess what the family members thought and how they felt about their involvement in their loved one's care.

The scale contains items such as “I feel like I have to be careful about how I make suggestions or requests about my relative’s care or staff will think I am interfering” and “I feel stressed between trying to give to my loved one with Alzheimer’s as well as to other family responsibilities, job, etc”. Results of the FPCR validated relative’s thoughts and feelings about having a loved one in care and sought to create a shared understanding about their experiences, necessary for a sense of cohesion in the support group. Subsequent support group sessions were designed around each family’s particular concerns and included topics on “What is a care plan?” “Creating a social or life history (for my relative in care)”, “What are the staff’s roles and what are they responsible for?” “How do I approach staff?”, “What is a case conference, and what is my role in a case conference?”

In general, families did not appear to have an understanding of the operations of the facility, even though some families had had a resident in care from months to years. Most families expressed relief at having their relative placed in a comparatively good facility. Mentors commented that the families who attended were not the most needy families, and the overriding feeling of the groups was “not to upset the apple cart” (family member’s words) concerning the systems and operations of the facility.

Experiences of the first family support group session

This will give you an idea of the focus and structure of the groups.

Our aims were to explore, and if possible prioritise, the key issues that are essential to provide effective support for families of residents with *behaviours of concern*. Where a resident did not have dementia, the aim was to explore and prioritise the key issues of most importance to families concerning the care of their loved one.

Our objectives were

- To create a climate of acceptance in the group through a relaxed, informal and private setting, the warmth of Mentor’s personal style and by agreement that matters raised in the group should be confidential unless otherwise agreed and to thank families for their involvement in the project.
- To reinforce the aims and methods of the overall project (in your case the program of changes occurring at your facility) and outlining changes taking place in the physical environment, the staff education, the Mentoring and family support.
- To set the tone of the group as a supportive and productive discussion about relatives’ feelings, concerns and issues (in contrast to groups that have developed into personal grievances about the facility).
- To examine similarities and differences between the project facilities regarding the project’s objectives.
- To present the aggregated results from the *FPCR* tool (This scale is attached at the end of this section and, although formal, may be a useful tool to pinpoint your residents’ families’ perceptions).
- To gain feedback from families about these results. This will involve going beyond the responses to discover why relatives feel the way they do and what factors, both positive and negative, may explain these results.
- To use these results and the discussion to decide what information will be of most benefit to families for up to two subsequent sessions. This may include a wide variety of topics, and may depend upon the level of comfort families feel with each other and the ‘maturity’ of the group, depending upon previous experience with them. Topics may include:
  - practical information about the facility
  - the practices and ‘rules’ of each facility
  - how to engage with the facility to be involved with the relative’s care
  - how to present useful information about their relative which can be incorporated into care practices and care plan
  - information about disease processes
  - emotional reactions and where to receive additional and appropriate support
  - permission giving by the facility such as ‘permission’ to attend to or resume other facets of the carer’s life
  - ‘permission’ to be involved in loved one’s care, and
  - other topics as appropriate.

Transition to regular sessions - the practicalities

Within our project, it was difficult to engage families in all seven facilities involved even with the support of the project team.

Four of the seven facilities had attempted to create family support groups with varying degrees of success before the project started:

- Two facilities ran a family session based on a ‘Resident Committee’ format that was primarily a practical information giving process about outings, laundry and staff changes
- One facility had attempted to create a family support group in association with their 8-place dementia specific wing, but ‘ran out of things to talk about’ (manager’s words) and discontinued sessions well before the project began
- One facility had a well attended monthly social ‘lunch out’ gathering for families and residents that provided an ad hoc family support network. Due to staff cuts this service was discontinued in the first few months of the project.

The project's family sessions were planned to commence after the Mentoring sessions had settled and become *business as usual* in the facilities. Three foundation group sessions were planned with the expectation that family sessions would continue and would be facilitated by a senior staff member from the facility.

Written invitations were sent to family members and the timing of the sessions was negotiated to take into account family obligations and the availability of a suitable venue.

The content of the three foundation sessions was based upon the three elements of successful family support discussed in the introduction to this section:

- Psychological support (e.g. expression of feelings)
- Educational support (e.g. information about dementia), and
- Support system development (e.g. encouragement to identify people in social networks who can offer support).

In particular, the foundation sessions aimed to:

- Address gaps in knowledge about dementia and other conditions that might contribute to behaviours causing concern
- To establish rapport in the highly diverse groups of people by encouraging a sense of shared experience and common purpose, and
- Develop ways to achieve greater involvement of families in informing staff about the residents' life stories and for contributing to the care planning process.

To establish a sense of shared experience, the sessions commenced with a short discussion of the aggregated results of the FPCR tool across the seven facilities. This had the effect of establishing "I am not alone" in my perceptions and allowed carers to bring up sensitive issues such as "I feel like an outsider in my relative's care" in a neutral, non-critical way. The topics stimulated families to reflect and describe their experiences and bring up areas of importance to them for exploration in subsequent sessions.

In each facility ongoing sessions were based upon the issues arising from the initial session. These included:

- *How do I communicate effectively with staff?* This topic was generated from repeated issues of carers not understanding the roles of staff, who they should communicate to about what, and the feeling that their resident would experience some undefined repercussions if the relative spoke out about care issues or concerns.
- *Letting go - how to let go, when to let go.* This session arose from the identification of the need for relatives to have more realistic expectations of the disease trajectory, their relative's abilities, and the abilities of the staff to address the myriad physical, social, behavioural, psychological andspiritual needs of the resident. This session encouraged families to talk with staff about partnering in care, to share ideas for suitable interaction or activities, and to appreciate family and staff points of view in the 'how' of delivering care.
- Practical workshop on the creation of a *Life Story* for residents. As well as a tool for reminiscence for the family with their resident, this workshop was designed to produce a communication tool for staff to appreciate the resident as a whole person, with a rich life story of achievements, disappointments, passions, events, tragedies and triumphs.
- A practical session on staff roles and responsibilities, and facility routines and practices in response to the FPCR question 'I don't know how things work around here'. This included talking about the care plan – what it was, how it is put together and how families can be involved in the development of a care plan and its review.
- General topics included ventilation of feelings, general education about dementia, the trajectory of the disease and its end stages, and the nature of *behaviours of concern*.

Setting up and running family support groups

Pointers and trouble shooting

Running a group can be highly rewarding but it can also be tough. Below are a few pointers that can assist you to run groups.

A support group in a facility can assist families to feel part of the facility, to be cared for, listened to and to learn from other families' experiences about what to expect and what is usual and normal to feel. It can help to normalise the experience of having a relative in care.

The groups serve a dual role. They provide both support and information and it's important to get a good balance between them.

At one of the early meetings, it's a good idea to get the group to set some ground rules about how they will interact, for example giving everyone an opportunity to express themselves; listen without being judgemental; problems can be aired, but not as personal criticism. This will encourage the members of the group to take ownership and self regulate.

Consider who will run the support group

Groups can be family led and run, or led by a senior member of staff, a diversional therapist, RN or chaplain.

The leader is a facilitator. A facilitator is a guide to help the group fulfil its purpose. In this case the purpose is to provide support and engender communication between staff and family to support the resident.

The facilitator needs to be someone who has experience in dealing with people who are under the strain of having a family member living in residential care and/or living with dementia.

> *One facility was very nervous about having a family group. They'd had resident meetings that involved families, and primarily the meeting was an information giving session. Staff dreaded the session. They felt certain families came to try to ventilate frustrations about their relative's dementia. Staff felt that these families stirred up discontent in other families.*
>
> *In the first family support session the facilitator laid down some basic group rules of confidentiality and respect. To the staff's amazement the other family group members managed the frustrations of the 'difficult' family, sympathizing with them, but relating how they had experienced the same issues, and dealt with them.*

A facilitator will listen and reflect; will co-ordinate and provide opportunities or arrange for the right person to address questions and concerns.

Consider the size of the group

Make sure the group is not too large. Generally between 8 – 16 people will be enough. Size will however depend on the topics discussed: a guest speaker style of group can be larger while an intimate discussion on feelings of grief will need to be small.

Consider the location

Generally a room that is away from the hustle and bustle of the facility – with a door that can be closed - is necessary. It needs to be comfortable, light, not noisy and with a pleasant ambient temperature. Think about the arrangement of seating to encourage eye contact and sharing.

> *One group was held in a little meeting room adjacent to a residents' lounge room.*
>
> *Residents would wander in from time to time. Rather than consider this a disruption, the facilitator incorporated these interruptions – encouraging carers to introduce their relative to the group. Families were delighted to learn that other families knew and interacted with their relative when they were not there.*

Managing time

As part of the ground rules, set the time. Facilitators can take certain discussions off line and suggest the most appropriate person or follow up action outside of the group.

Family support on a one-to-one basis

Mentors also had contact with families outside of formal family sessions. These were conducted in close co-operation with the facility. Reasons for meetings (some of which were case conferences) included:

- Implementation of a specific behavioural program
- A significant change in resident's' condition (such as commencing palliative care), or
- Family social events in which they wished residents to be involved, such as co-coordinating a resident's attendance at a family wedding, or arranging a last trip to see the resident's farm and home.

Difficult situations

Accidental counselling

Sometimes in family support groups issues arise that the facilitator needs to address, but is not sure how to respond. It is OK to refer people on for professional help. Remember you are there to guide, not to have all the answers.

When things take a downward turn

It can be easy to get in to a negative spiral. Some useful phrases to use to turn a negative conversation around include:

- *"You've said what you don't want to happen Joyce. Can you tell us what you would like to see happen?"*
- *"Let's separate the person from the issue;"*
- *"Some people have become very quiet. Can you tell us what is going on for you?"*

For more information on this, a useful resource is the book *The Art of Facilitation*[28] the details of which are included in the reference list at the end of this Toolkit.

When people cry

Talking about caring and watching a loved one decline is a confronting and emotional experience. Tears are normal - so have tissues handy.

Problems and possible solutions:

The family support groups were the most difficult component of the project to implement and maintain. Families were busy and already had routines when it came to the timing and frequency of their visits. Starting a group from scratch and recruiting families to join it was difficult and sometimes produced few results.

We found that those residents who were selected to be a part of this project due to their *behaviours of concern* were less likely to have existing family support networks. This may have been because their behaviours were made worse by other psychological or social issues which had cut them off from their families in the past. For this reason, those residents who would have benefited most from greater family support (and information transfer from family to staff) were those who were least likely to receive it.

The Carers NSW *Setting up a Carer Support Group* Information resource (www.carersnsw.asn.au) provides the following tips in helping manage emotions in a group:

- Acknowledge people's experiences
- Be aware of confidentiality
- Don't feel you always need to have an answer
- Share the job with a co-facilitator
- Be reasonable in your expectations of group's members
- Be prepared to examine your own behaviour
- If group members need more help, have a list of services to which you can refer them.

The Family Perceptions of Care-giving Role (FPCR) Tool can be found in the evaluation section of this toolkit.

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BETTER DESIGN

Our experiences

This section explains the process we undertook to evaluate the existing environment at each facility and to find ways of improving the liveability of the spaces where residents spend a lot of time.

We have included the Environmental Audit Tool (EAT), so that you can also the environment of your facility and think about opportunities for improvement.

Background

The project began with the selection of the seven facilities across New South Wales and Victoria. The facilities were chosen because they represented typical, residential facilities. They were not new, had no strong links with specialised services and five of the seven facilities were not based in the better serviced metropolitan areas. A NSW Health Multi-Purpose Service was included because of the significant number of elderly people living in such services across NSW and because their roots in the health care system sometimes provided a challenge to changing aspects of the environment.

Among these facilities there was probably one quite similar to yours.

Process

The first step we took was an environmental audit of each facility. This was done by the project architect using the EAT (provided in this section). The EAT was used to evaluate and score the physical design and fit out of the environment. The EAT evaluates how the design enhances or limits the abilities of people with dementia against a set of key, evidence- based design principles.

The results of the audit were used to highlight areas which could be improved. These results were discussed with the managers and staff and a plan formulated. The plan included immediate changes through re-using existing resources, e.g. re-arranging the furniture and short term and inexpensive changes, e.g. selecting paint colours to be used in routine maintenance that would highlight what residents need to see and use, such as handrails. Planning also began for mid to long term changes requiring capital works and access to more substantial funding.

While the environmental changes were being discussed the staff and managers were asked to identify people in their facility whose behaviours were causing concern. There was a wide range of behaviours of concern across the facilities. One facility had few active behaviours of concern (e.g. aggression) but several very withdrawn residents. Other facilities had high levels of resident agitation and aggression.

The project was fortunate to have an experienced architect as part of the team. However, the EAT is easy to use, so not having an architect involved is not a barrier to making small, innovative changes which can have an immediate, positive effect.

The discussions on the environmental changes occupied the first three months of the project and provided an excellent opportunity for building a relationship with the managers and staff.

Environmental changes almost always took longer than expected and some were still in the process of completion at the end of the project. However the environmental audit conducted at the conclusion of the project showed positive changes had occurred in the targeted areas of each facility.

Lessons learnt

- The process of introducing environmental changes into the seven facilities highlighted the need for local leadership. Without an on-site *Champion* who understands and values the proposed environmental changes there is little chance that change will occur. Identifying the modifications needed, finding the resources, negotiating with the suppliers and tradesmen, manage the impact on the staff, families and the residents, and encouraging full use of the new amenities, takes time!
- A budget for environmental modifications is necessary. While some changes can be achieved by using what is already in a facility differently (for example, rearranging a storage area as a quiet room), many modifications require a budget. If a budget exists, it may take time to obtain approvals. Several modifications proposed at the beginning of the project remained incomplete at the conclusion of the project eighteen months later.
- Allowance often needs to be made in the operating budget for environmental modifications. For example, the creation of a pleasant area for family and resident get togethers meant having hospitality staff maintain supplies and equipment for beverages and snacks.
- Staff and management time are required to plan and implement change, so there will be costs, whether consultants are involved or not. Encouraging staff involvement in the process is beneficial in the long run. In our experience, the ability to have staff dedicate time to understand and help plan environmental change was a key factor in determining whether the environmental modifications were made and utilised as intended.
- Time is needed as well as money. In this project money was available for furniture purchases, but staff found it difficult to find time to make appropriate, well thought out selections.
- One of the biggest lessons we learned is that getting things happening can take a long time. It is important to expect this and to keep hold of the vision!

If you have an opportunity for substantial changes, don't be afraid to think big. But if huge changes aren't possible at your facility, don't give up altogether!

Simply starting is important: it is worth painting that one wall in the lounge. If you have little or no money, go for the simple things. While it may be difficult to build a new fence of a more suitable design or alter the site perimeter, unlocking a door to a garden area can be done easily: a simple action that can have an immediate environmental impact. Perhaps the greatest legacy of the project will not be that significant building works have been undertaken, but rather that staff and managers now think about the environment as a resource to improve quality of life and increase opportunities for meaningful activity. As routine maintenance tasks come up, staff are alerted to think more about the opportunities they have to make an impact. In a number of instances staff or managers rang up to let us know that they had been able to purchase furniture or undertake painting that they hadn't expected. Understanding how the environment can be used as a tool to help them achieve care goals and provided strong justification for expenditure.

CASE STUDY

Small changes making a big difference

Designed some years ago, this facility was a U-shaped, two-storey building with bedrooms opening off corridors, a dining room at one end of the U and a lounge at the other. The lounge room on the ground floor is the only social space for residents. It is a large room with windows to the outside and a kitchenette.

When the project started the kitchenette had a old, small folding card table with a couple of well-used vinyl chairs. A drinks machine dominated the space. There had been an unsuccessful attempt to run a café for residents from this area. The kitchenette opened onto the lounge room which was dominated by a row of chairs lined up to face a flat-screen TV. Some residents had their favourite seats and took charge of the TV. It was difficult for others to find a place in the room, and not all residents felt welcome, even though it was the only lounge room for the seventeen low care residents who live on the ground floor.

As part of the project, we identified that there was a great need for more social spaces in the building. Resources were limited, and because the building was old and there seemed to be little sense in spending significant money on alterations. The challenge was how to make the most of what was already there.

As the kitchenette was little used, staff thought about turning it into an Information Technology area. We advised against this, and focussed instead on making the kitchenette more appealing.

We began by changing the furniture in the kitchenette, replacing the old table and chairs with a new timber country-style setting, with an inviting warm finish. While small, it was cosy, fitting well into the space and creating a sense of kitchen - dining room. It was not possible to remove the drinks machine but it no longer has the same prominence because of the presence of the new furniture.

A portable screen was then purchased so the kitchenette could be separated from the lounge room. While this is largely a visual separation and doesn't help with noise, it has a significant impact on the feel of the space. When sitting at the table you no longer focus on the lounge, and instead are aware of being in a much more intimate setting. It is also significant that the screen is beautiful with a striking picture in gold and reds and greens. It is not an ordinary 'off-the-shelf' screen and in no way has a 'make-do' feel. It is something that is lovely to look at. It can be put up and removed easily, and when not in use does not take up much room.

The introduction of a new dining-table and chairs and painted screen has given a new lease of life to the lounge and kitchenette. Residents and families feel welcome to come and sit in the kitchenette. The lounge and kitchenette can be used simultaneously and there is good visual separation between the two spaces. The kitchenette is inviting and its purpose clear. Residents and their friends and families now have a pleasant place to sit and share a cuppa or a meal. It is amazing what a difference some furniture can make!


Before


After


After


After

The Environmental Audit Tool (EAT)[25]

People living with dementia, and indeed all older people in aged care can be helped or harmed by the physical environment in which they live. This observation is backed by more than 25 years of research. While the research is wide ranging, it can be summarised into ten major principles. These are the principles that underpin the EAT.

Design Principles

An environment that is to be used to provide care aimed at maintaining the abilities of older people and people living with dementia should:	
1. Be safe and secure	The confusion which accompanies dementia determines the need for a variety of safety features to be built into the environment. They include a secure perimeter, hot water temperature control and safety switches in the kitchen. Safety features must not be obvious as this leads to people feeling trapped.
2. Be small	The larger a facility is the more confusing it is likely to be for residents. High quality care is easier to provide for small groups.
3. Be simple and have ability to see and be seen	Confusion may be reduced by simplifying the environment so a resident can see everywhere that she wants to go to from wherever she is. This principle limits the inclusion of corridors in new designs and means the staff should be able to see the residents almost all of the time. This reduces anxiety in both staff and residents.
4. Reduce unwanted stimulation	People living with dementia experience difficulties in coping with large amounts or competing sources of stimulation, (for example having the television on while eating a meal). The facility must be designed to reduce the impact of unnecessary stimulation, especially noise. For example, entry and exit doors used for deliveries and staff movements should not be visible to the residents, nor should there be audible staff paging systems.
5. Highlight important features	Features that are important to the residents should be highlighted. These include toilet doors, exits to safe outside areas, and orientation aids such as signs, pictures or objects to help them recognise their room.
6. Provide for planned walking (wandering)	Walking (sometimes referred to as wandering) is sometimes a feature of the person with dementia. The design should allow walking to take place safely, but not encourage agitated pacing. The walking path should provide an opportunity for the person to go outside and take them past areas of interest in the expectation that they will provide the person with alternative activities to repetitive walking or pacing.
7. Be familiar	A person living with dementia recalls the distant past more easily than the recent past. To ensure that their experience of their surroundings is in keeping with their mental state, fixtures and fittings should be like those that would have been familiar to the residents from their early adulthood.
8. Provide opportunities for privacy and community	People with dementia require a variety of opportunities for social interaction. Spaces are needed for sitting quietly alone, just observing what is going on or with one or two friends, and also in larger groups.
9. Provide links to the community	To provide opportunity for residents to continue to be part of their community after moving into aged care, access to shopping, their church, parks and social clubs should be facilitated. If getting outside is difficult, consider what the resident sees from her window, and whether this provides an opportunity for interaction with everyday life. Create private spaces for visits.
10. Be domestic	The facility is the residents' home; therefore the environment should be as homelike as possible. In the absence of a cure for dementia, the goal of care is to maintain the person's abilities for as long as possible. This requires opportunities and encouragement to use those abilities in normal everyday tasks. All of the features found in a domestic home should be provided, including a kitchen, laundry, garden and social spaces.

Instructions for completion of the Environmental Audit Tool

Step 1. Answer the questions

Answer the questions in order. Circle the appropriate response.

Questions can be completed in about 10 minutes by a person working alone.

Questions can also be completed by a group. This will stimulate staff discussion of the strengths and weakness of the environment. While this will take longer, it will lead to a greater variety of suggestions for change.

Step 2. Score the answers

Total the scores. Complete the summary of scores table. Add up the scores for each section and write in the ‘actual score’ column. Calculate the percentage of actual score /possible (or best) score. This is the “room for improvement score”.

Step 3. Review and make suggestions for improvements

Review the answers to the questions and make suggestions for applying each principle. The suggestions of positive change can be sorted in to short term inexpensive changes; medium term or more costly changes and long term major works. The table titled “Suggestions for improvement” may be useful to organise your results into goals and strategies for achievement.

Important features should be clearly visible, so that residents can make choices and use the abilities they retain.

Step 1: Environmental Audit Tool

Facility: Date: Time:

Unit/Area: Number of residents when full:

Observer:

Safety	**N/A**	**NO**	**YES**	**Add 1 if Unobtrusive**	**Score**
1. Is the garden secure, i.e. are residents prevented from getting over/under fence or out of the gate without the assistance of a staff member?	0	0	1	1	Saf1
2. If the front door leads out of the unit is it secure?	0	0	1	1	Saf2
3. Are all side doors leading out of the unit secure?	0	0	1	1	Saf3
4. Are bedroom windows restricted in the extent to which they open so that residents cannot climb out?	0	0	1	1	Saf4
5. Is the garden easily supervised from the point(s) where staff spend most of their time?	0	0	1	1	Saf5
6. Is there a way to keep residents who are not safe with knives and/or appliances out of the kitchen?	0	0	1	1	Saf6
7. If the kitchen is used by residents is there a lockable knife draw in the kitchen?	0	0	1	1	Saf7
8. If the kitchen is used by residents is the stove a gas?	0	0	1		Saf7
9. If the kitchen is used by residents is there a master switch that can be turned off quickly?	0	0	1		Saf9
10. Is the temperature of the water from all taps accessible to residents limited so that it cannot scald?	0	0	1		Saf10
11. If residents are involved in meal preparation are the pots and pans used small enough for them to lift easily?	0	0	1		Saf11
12. Are all floor areas safe from being slippery when wet (water or urine)?	0	0	1		Saf12
13. Is the lounge room easily supervised from the point(s) where the staff spend most of their time?	0	0	1	1	Saf13
14. Are all areas used by residents well lit?	0	0	1		Saf14
Total					**Saftot**

Size	**10 or less**	**11-16**	**16-30**	**30+**	**Score**
1. How many people live in the unit?	Score 3	Score 2	Score 1	Score 0	Size

	Visual Access Features							Score
1.	What proportion of confused residents can see their bedroom door from the lounge room?	N/A	0 Score 0	25% Score 1	50% Score 2	75% Score 3	100% Score 4	Vis1
2.	What proportion of confused residents can see the lounge room as soon as they leave their bedroom?	N/A	0 Score 0	25% Score 1	50% Score 2	75% Score 3	100% Score 4	Vis2
3.	What proportion of confused residents can see the dining room as soon as they leave their bedroom?	N/A	0 Score 0	25% Score 1	50% Score 2	75% Score 3	100% Score 4	Vis3
4.	Can the exit to the garden be seen from the lounge room? If there is more than 1 lounge room answer with reference to the one most used by most confused residents.	N/A	NO Score 0		YES Score 1			Vis4
5.	Can the dining room be seen into from the lounge room? If there is more than 1 dining room or lounge room answer with reference to those used by most confused residents.	N/A	NO Score 0		YES Score 1			Vis5
6.	Can the kitchen be seen into from the lounge room? If there is more than 1 lounge room answer with reference to the one used by most confused residents.	N/A	NO Score 0		YES Score 1			Vis6
7.	Can the kitchen be seen into from the dining room? If there is more than 1 dining room answer with reference to the one used by most confused residents.	N/A	NO Score 0		YES Score 1			Vis7
8.	Can a toilet be seen from the dining room? If there is more than 1 dinging room answer with reference to the one used by most confused residents.	N/A	NO Score 0		YES Score 1			Vis8
9.	Can a toilet be seen from the lounge room? If there is more than 1 lounge room answer with reference to the one used by most confused residents.	N/A	NO Score 0		YES Score 1			Vis9
10.	Can the lounge room be seen into from the point(s) where staff spend most of their time?	N/A	NO Score 0		YES Score 1			Vis10
Total Score								**vistot**

	Stimulus reduction features	Yes	No	Score
1.	Does the doorbell attract the attention of the residents?	0	1	Stim1
2.	Is the noise from the kitchen distracting for the residents?	0	1	Stim2
3.	Are doors to cleaner's cupboards, storerooms and other areas where residents may find danger easily seen (i.e. not hidden or painted to merge with the walls?)	0	1	Stim3
4.	Is the wardrobe that the resident uses full of a confusing number of clothes?	0	1	Stim4
5.	Are deliveries of food, linen etc. taken across public areas such as the lounge or dining room?	0	1	Stim5
6.	Is there a public address, staff paging or call system in use that involves the use of loud speakers, flashing lights, bells etc?	0	1	Stim6
7.	Is the front entry to the unit easily visible to the residents?	0	1	Stim7
8.	Is the service entry (where food, linen etc is delivered to) easily visible to the residents?	0	1	Stim8
Score is number of NO responses				**stimtot**

	Highlighting useful stimuli	NO	YES	Score
1.	Is the dining room looked into from the lounge room or clearly marked with a sign or symbol?	0	1	High1
2.	Is the lounge room either looked into from the dining room or clearly marked with a sign or symbol?	0	1	High2
3.	Do bedrooms have a sign, symbol or display that identifies them as belonging to a particular individual?	0	1	High3
4.	Are the shared bathrooms and/or toilets clearly marked with a sign, symbol or colour coded door?	0	1	High4
5.	Is the kitchen either looked into from the lounge or dining room or clearly marked with a sign or symbol?	0	1	High5
6.	Are toilets visible as soon as the toilet/bathroom door is opened?	0	1	High6
7.	Is there a lot of natural lighting in the lounge room?	0	1	High7
8.	Is the artificial lighting bright enough in all areas?	0	1	High8
9.	Is the lighting free of glare, eg from bare bulbs, off shiny surfaces?	0	1	High9
Score is number of YES responses				**hightot**

	Provision for walking and access to outside area	NO	YES	Score
1a	Is there a clearly defined and easily accessible (i.e. no locked exit) path in the garden that guides the resident back to their starting point without taking them into a blind alley?	0	1	Wand1a
1b	Does the external path allow the resident to see into areas that might invite participation in an appropriate activity other than wandering?	0	1	Wand1b
1c	Is the path within a secure perimeter	0	1	Wand1c
1d	Can this path be easily and unobtrusively surveyed by staff members?	0	1	Wand1d
1e	Are there chairs or benches along the path where people can sit and enjoy the fresh air?	0	1	Wand1e
1f	Are there both sunny and shady areas along the path?	0	1	Wand1f
1g	Does the path take residents past a toilet?	0	1	Wand1g
2a	Is there a clearly defined path inside that takes the resident around outdoor furniture and back to their starting point without taking them into a blind alley?	0	1	Wand2a
2b	Does the internal path allow the resident to see into areas that might invite participation in an appropriate activity other wandering?	0	1	Wand2b
Score is number of YES responses				**Wandtot**

Familiarity		**Many**	**A few**	**None**	**Score**
1.	Are there any colours in the furnishings or the decoration that would not have been familiar to the majority of residents when they were 30 years old?	0	1	2	Fam1
2.	Are there any taps, light switches, door knobs that are to be used by residents that are of a design that would not have been familiar to the majority of residents when they were 30 years old?	0	1	2	Fam2
3.	Are there any pieces of furniture in the lounge room or the dining room that are of a design that would not have been familiar to the majority of residents when they were 30 years old?	0	1	2	Fam3
4.	Are there any pieces of furniture in the bedrooms that are of a design that would not have been familiar to the majority of residents when they were 30 years old?	0	1	2	Fam4
5.	How many residents have their own ornaments, photos in their bedroom?	2	1	0	Fam5
6.	How many residents have their own furniture in their bedroom?	2	1	0	Fam6
Total Score					**Famtot**

Privacy and Community						**Score**
1	Are there small areas (nooks) that provide opportunities for casual interaction and quiet chats?	None Score 0	1 Score 1	2 Score 2	3 or more Score 3	Priv1
2	How many of these areas or nooks have views of pleasant or interesting scenes (outside, the living room, the nursing station)?	None Score 0	1 Score 1	2 Score 2	3 or more Score 3	Priv2
3	Do the shared living areas support small group activities (4-6 people) without re-arranging the furniture?	N/A	NO Score 1	YES Score 2		Priv3
4	Does the dining room provide opportunities for residents to eat in small groups (2-4)?	N/A	NO Score 1	YES Score 2		Priv4
5	Does the dining area provide opportunities for people to eat alone?	N/A	NO Score 1	YES Score 2		Priv5
Total Score						**Privtot**

Community links		**NO**	**YES**	**Score**
1.	Is there an area or room somewhat removed from the main dining room where families can share meals with their relatives?	0	1	Com1
1a	Is this room/area domestic and familiar in nature, to reassure family members and friends and encourage them to visit and to participate in the care of the resident?	0	1	Com1b
Score is number of YES responses				**Comtot**

	DOMESTIC ACTIVITY **Record the percentage of residents who:-**	**None**	**Up to 50%**	**More Than 50%**	**Score**
1.	Have access to a kitchen	0	1	2	Dom1
2.	Have a significant involvement in main meal preparation	0	1	2	Dom2
3.	Have a significant involvement in making snacks or drinks	0	1	2	Dom3
4.	Have a significant involvement in keeping bedroom clean and tidy	0	1	2	Dom4
5.	Have a significant involvement in personal laundry	0	1	2	Dom5
6.	Are involved in gardening	0	1	2	Dom6
7.	Have constant and easy access to a lounge?	0	1	2	Dom7
8.	Have constant and easy access to a dining room?	0	1	2	Dom8
Total Score					**Domtot**

Step 2: Score the answers and sum the scores

* The percentage of actual score /possible (or best) score is your “room for improvement score”.

Summary of scores

	Possible Score	**Actual Score**	**Percentage***
Safety	14		
Size	3		
Visual Access	10		
Stimulus Reduction	8		
Stimulus Enhancement	9		
Wandering And Access Outside	9		
Familiarity	12		
Privacy And Community	12		
Community Access	2		
Domestic Activities	16		
Total	**95**		

Step 3: Suggestions for improvement

List the **short term goals** you could set to improve the quality of your environment for people with dementia and then briefly describe how you will achieve it (strategy).

	Short term goals	Strategy
1. Be safe and secure		
2. Small		
3. Simple and have good ‘visual access’		
4. Reduced unwanted stimulation		
5. Highlight important stimuli		
6. Provide for planned walking		
7. Familiar decor		
8. Provide opportunities for privacy and community		
9. Links to the community		
10. Domestic		

List the **medium and long term goals** you could set to improve the quality of your environment for people with dementia and then briefly describe how you will achieve them (strategy).

	Long term goals	Strategy
1. Be safe and secure		
2. Small		
3. Simple and have good ‘visual access’		
4. Reduced unwanted stimulation		
5. Highlight important stimuli		
6. Provide for planned wandering		
7. Familiar decor		
8. Provide opportunities for privacy and community		
9. Links to the community		
10. Domestic		

Some examples of what we did

- **How did we *re-use* what is there?**
  - Re arranged furniture to create small conversational groupings (rather than having chairs lined up around the perimeter of the room)
  - Re arranged furniture to give a focus to look outside – that is, place chairs to enable to occupant to see out the window. We even did this with beds to give non-ambulant residents a view to the outside from their beds
  - Encourage residents and families to bring small pieces of furniture and decoration, not only for residents rooms, but for communal areas as well
  - Unlocked a door to a courtyard, moved outdoor furniture to provide an easy to reach destination that was visible from inside, encouraging residents to go outside
  - Opened sheer curtains to give a view to the outside, and incorporated this as part of the staff breakfast routine
  - Worked on appropriate storage of equipment to open up new sitting nooks for residents and families
  - Removed non-essential institutional symbols and staff-only relevant notices from residents' areas
  - Introduced two lounge chairs and a tv into the room of the only two men in the facility, to create a "blokes' den"
- **What did we do in the *short* term?**
  - Use paint colour and features (eg shadow boxes, artworks) to create different identities in different corridors and parts of corridors, also to distinguish between doors in corridors
  - Introduce cueing through colour, objects and signage to corridor to identify location of nooks, activity, dining/lounge area and distinguish each from other areas
  - Introduce some new pieces of furniture and create more private areas within dining/lounge room
  - Introduce feature colours and decorative friezes to enliven the atmosphere to walls of dining/lounge room, bedroom doors, wet areas
  - Altered finish to bedroom doors to distinguish between ensuite and bedroom doors
  - Painted handrails to contrast with walls, making them easier to see and use
  - Disguised 'staff only' doors by painting the door and architrave the same colour as the surrounding wall
  - Introduce shelves and/or cupboards for residents' toiletries to wet areas
  - Introduce towel rails to wet areas
  - Allowed courtyard access and signposted way back to dining/lounge room
  - Encouraged use of unused garden areas as sitting/activity area
- **What did we do or plan for the *medium* term?**
  - Made alterations to the entry to create an additional vestibule to give "airlock" between the front door and the resident's area
  - Introduce raised garden beds, garden beds, pots with edible herbs, garden seats and other features such as a bird bath to create a for interest and engagement
- **What did we plan for the *long* term?**
  - Reworked floor plan to open up lounge areas; give visual access to the garden; better situate the Director of Nursing and staff area; created an additional bed for the nursing home
  - Replace stainless steel grab rails in ensuites with colour themed, powdercoat grab rails that highlighted the rails and made them easier for residents to see and use.

Applying the design principles

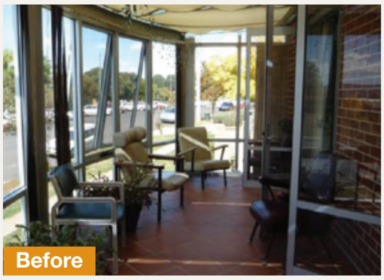
Reponses to the design principles should always be made in the context of the individual facility.

What is familiar and/or meaningful will always be influenced by where a person lives. Socio-economic factors, climate and landscape are just some of the things that have an impact on people's lives and influence how they live. That said, a number of common actions emerged in the project. Adding colour to a room, for example, was recommended in all facilities. How the colour is applied (for example to a feature wall or a ceiling), where the colour is applied (say to a lounge room or corridor) and what the colour is was different in every setting.

Following are some case studies of the changes that were made to environments as part of the project. There are often many issues that could be addressed in the one space.

An unused verandah to an inviting sitting room

CASE STUDY



Principles Applied:
Domestic, Familiar, Opportunities for Privacy and Community

The verandah in this facility is a room which was not used often, despite an interesting view of the street and a chance to observe what was going on. It tended to be used as an equipment store room. Following our conversations, the verandah went through two transformations: initially the stored equipment was removed and chairs and plants brought in (before photo). Doors that had been shut were routinely opened to encourage residents onto the verandah. The facility then raised some money to purchase attractive and functional chairs, and positioned them to take advantage of the view (after).

Why is this important?

Providing new furniture has made the most of a space which is already there and provides a much needed second social space. Selecting cane furniture ensured that the room has a really different feel to the adjacent lounge-dining room. It builds on the light and airy feel of the space with its floor to ceiling windows. It introduces variety and diversity into the environment and gives residents a chance to spend time in rooms which offer them a different experience. The verandah became a favourite destination for residents and families.

Where's my room? Using signage to help

CASE STUDY

Principles Applied:
Domestic, Reduce Unwanted Stimulation, Familiar

As this facility is part of a hospital, there was a requirement to provide patient records and medication information. This was affixed outside each bedroom door – a basket for a notes folder and medication was in a locked cabinet with a medical cross on the exterior.

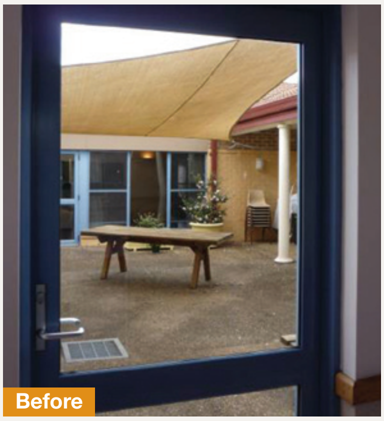
Following conversations, the cross was removed and a photo of the residents' choice was placed on the cabinet instead so that the entry to the room is more personal. There are plans to make further changes and the introduction of a painting to screen the cabinet and records or introduce a cabinet with a timber finish is being considered.

Why is this important?

While the removal of the medical cross from the cabinet is a relatively simple change which has only a small impact, it is nonetheless a change for the better. It is important not to underestimate the worth of making a start. Small things do matter! This change was able to be done quickly, cost nothing and does not limit the opportunity for a more significant change to take place in the future. It may even give it some momentum. Residents appeared to enjoy the affirmation of having something of their choosing identifying their own room.

Using a courtyard

CASE STUDY


Before


After

Principles Applied:
Visual Access, Reduce Unwanted Stimulation,
Opportunities for Privacy and Community, Domestic

The door to the courtyard in this facility was closed and locked, obviously limiting the use of the courtyard. There was no particular reason to limit access, and locking the door simply seemed to have become habit. Chairs were stacked, and the space had a disused, unloved appearance. Advantages were that the area had shade cloth installed and existing garden furniture.

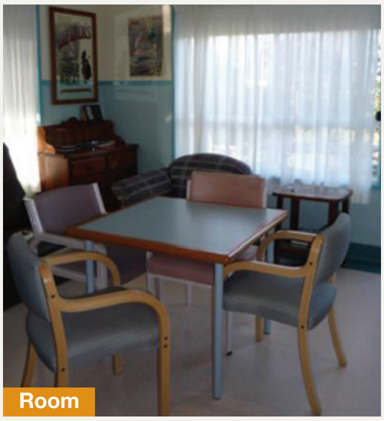
Following discussions with staff, the doors are now left open to encourage residents to use this space. As the courtyard is located centrally, it can easily be seen from the lounge and dining room. It also offers residents a clear view of where they can go, and how to leave the courtyard.

Why is this important?

The courtyard offers an opportunity for residents to spend time outside and is a pleasant alternative to the lounge and dining rooms. Opening the door has meant that a space which already existed is used more. This also gave residents a destination and improved flow through ventilation in the unit.

Nook

CASE STUDY


Room


View

Principles Applied:
Highlight Important Stimuli, Familiar,
Opportunities for Privacy and Community

When we visited this nook the room was dull and was not an inviting place to be.

Then we discovered that it looked out on a beautiful garden! The curtain had been closed because night staff were concerned that people could look into the facility. There was not, however, a routine to open the curtain again in the morning. The curtain was opened and 'hey presto'!

Why is this important?

This is another great example of how to make the most of what is already there. The character and appeal of the room alters enormously when there is view to the garden. It is an easy way to address the lack of alternative social spaces that the facility experienced.

And just look at the view that was being missed out on!

For inspiration

The environment is an important tool to use to encourage appropriate activity, and provide a ambience in which residents feel comfortable and 'at home'. A thoughtful, well designed environment, whether new, old or refurbished has plenty of scope for change for the better. Here is a list simply to get you thinking....

How can we *re-use* what is there?

- Encourage residents and families to bring small pieces of (appropriate) furniture and decoration for residents' rooms or bed areas, but also for the social spaces
- Use increased levels of lighting – leave the lights on - and use appropriate music to draw residents to social spaces
- Review your storage for institutional equipment and remove trolleys, lifters and wheelchairs from corridors, provide instead attractive nooks and seating to encourage residents to walk and explore
- Take a moment and sit where a resident sits. What do they see? Open curtains, turn the chairs to take advantage of the view, or position chairs where residents can sit and just observe what is going on
- Think about the TV... and limit its use. Consider locating the TV to a specific television area rather than dominating a main living space
- What is on the walls? Look at artwork, notices, fire extinguishers, emergency signs... consider the height of artwork – can a seated resident see it? Remove 'staff only' notices in resident areas; minimise the use of white boards and notice boards and get rid of temporary signs!
- Can residents get outside? Unlock the doors to safe outside spaces
- Ready the environment for use. Unstack staked chairs and place in 'conversational groupings", open the lid of the piano and place music on the music desk, leave books, magazines open at inviting colour pictures, leave a feather duster out...

What can we do in the *short* term?

- Use colour and features (e.g. shadow boxes, distinctive paintings, or memorable objects such as a grandfather clock) to create different identities in different corridors and to distinguish different parts of your facility
- When ordering new furniture, choose sturdy, domestic style furniture that will be familiar to the resident. Does your dining room look like a dining room or a cafeteria?
- Create distinct areas in a large dining room. For example, breakup a "uniform look" by using clusters of small tables with different, co-ordinating colours of table cloths or chair upholstery
- Choose chairs with arms, and with seat upholstery that provides good visual contrast to the floor
- Provide new entry doors with domestic finish such as panelling or beading
- Use routine painting maintenance to highlight features residents need to see and use: paint handrails in a feature colour that contrast with the background wall; clearly differentiate bathroom/toilet doors from bedroom doors; and paint staff only doors and architraves to blend with the background wall colour
- Screen or disguise doorways to commercial kitchens, pan rooms, utility rooms and other 'staff only' areas
- Look for unused space, such as the end of corridors (hint- this is where you usually find the lifter parked!) Introduce new furniture to create private sitting nooks, family visiting areas or 'sun traps'
- If re-upholstering chairs, or purchasing new lounge or dining furniture, make sure the seat upholstery contrasts well with the floor to help residents 'see' where the chair is against its background
- If replacing toilet seats, choose colours that contrast with the pan and surrounds to help residents see where the toilet is
- Use finishes – floor coverings and curtains - that increase thermal efficiency and absorb sound
- Consider what bed-bound residents see from their beds. Consider relocating the bed to give a view
- Review function of door closers, introduce sound absorption to corridors and door jambs
- Provide interesting destinations! If another resident's room is the most interesting space, that is where some residents will gravitate to!
- Introduce shelves and/or cupboards for residents' toiletries to wet areas
- Introduce towel rails and towels which contrast with the walls to wet areas (to act as a cue for residents)
- Review the identification on resident's rooms/ spaces. A current photo will be meaningless for the resident. Make it in to an activity to find pictures or objects individuals identify with and gravitate towards
- Review the signage relevant for residents. Is the toilet clearly marked in words (in appropriate languages) and with a clear picture? Is the base of the sign 1.2 m from the floor?
- Introduce unobtrusive fencing to create garden areas for residents to use (check what is required for emergency assembly area outside first)
- Create interesting outside spaces, provide seating with a view, shade and sun, and opportunities for activity – raised garden beds, pots with edible herbs

What can we do in the *medium* term?

- Introduce more consistent and higher levels of light! The elderly eye needs twice the light levels of a younger adult. Use natural light, higher wattage bulbs, open curtains
- Introduce feature light fittings at decision points in corridors to help with wayfinding

- Provide a resident and family kitchenette with bench, cupboards, shelves, sink, and microwave to provide opportunity for activity with visiting relatives
- Introduce picture rails in bedrooms to encourage residents to bring in pictures (without the maintenance hassles)

What can we plan for in the *long* term?

- Consider the size of the home, and reducing it into smaller sections or groupings
- Consider the relationship between staff nursing stations and where residents spend most of their time. Do staff have ability to see most of the residents? Can residents see and sense where staff are?
- Is there easy access for residents to spend time outside? Consider access to safe outside spaces, places to walk and features that residents will enjoy to interact with are visible and inviting
- Consider the amount of noise in the home. Install silent or vibrating nurse call systems, use sound absorbent finishes
- Use consistent colour and tone in all floor surfaces, both indoor and outdoor, to avoid mistaking colour change as a step or drop in level
- Provide a variety of social spaces that give residents choice where to spend their time

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[29] The Environmental Audit Tool is taken from;Fleming, R., Forbes I., et al. (2003). Adapting the ward for people with dementia. Sydney, NSW Department of Health.

BETTER OUTCOMES

Our experiences

While the changes recommended as part of this project aimed to be achievable and affordable, there are still costs involved, both in terms of capital costs (especially for changes to the environment) and staff time. It is our belief, however, that the benefits outweigh the costs. Not only will the standard of care in your facility improve, but investment in these changes could potentially decrease other costs over time.

In our experience, investment in staff training and Mentoring (the major outlay for the project) improved staff retention, generating significant savings in recruitment and training costs. While we did not undertake to project with a financial objective in mind, improving quality of life and the morale of staff and families can create financial (as well as quality of life) dividends over the long term.

This section includes a selection of results from our project. If you wish to read a copy of the full report, please email dementiacentre@hammond.com.au, for more information. This report also contains the references used to inform the project.

Following this section there are a number of tools you can use to evaluate to effectiveness of changes in your facility. Although you may not have the same sort of reporting requirements a research project has, it may be helpful for you to have results to show, in order to convince funders to support changes in the long term. Improved results are also an encouragement for you and the rest of the team.

Selected results from the project:

We assessed if the interventions had an impact on the residents, particularly on the level of behaviours of concern, psychiatric symptoms and depression.

We also assessed if there was demonstrable change in each of the project target areas; environmental changes, staff knowledge and attitudes, staff stress, staff views on the process and results of the project, family satisfaction with and perceptions of care and the process of the project.

Impact on residents

Between six and nine residents were selected by senior staff in each of the seven facilities because their behaviour was causing concern to them, the staff or their families. Residents mean age was 81.3 years at the commencement of the project, 39% were male and 70% had a diagnosis of dementia.

We assessed the residents every two months on scales of behaviour and psychiatric symptoms, using the Cohen-Mansfield Agitation Inventory[30] (CMAI) and the Neuropsychiatric Inventory – Nursing Home version (NPI –NH[31]). We measured depression at 3 time points, using the Cornell Depression Rating Scale.[32]

The baseline, or pre-intervention assessment showed that 48% of residents had major symptoms of depression. The amount and type of overt behaviours of concern (eg agitation or aggression) as measured by the CMAI, were significantly different between facilities; the residents in the project in some facilities were significantly more agitated than those in others; however the changes that took place in all facilities were similar.

Changes in CMAI Scores

The graph below charts the steady decline in agitated behaviour over the course of the project. The lower the score, the better. The reduction is statistically significant, that is, we are confident the result was not due to chance (beta+-3.458, p<.001, 95%CI -4.25).

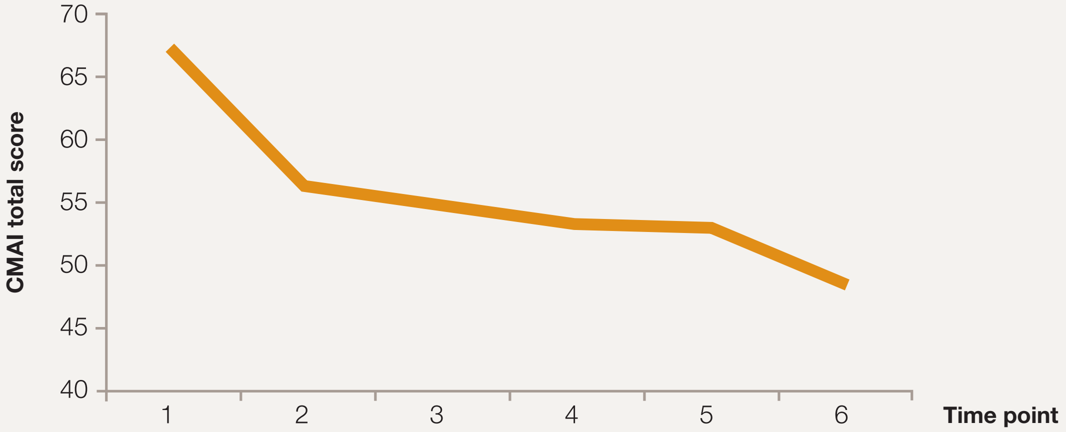
Changes in NPI-NH scores

Analysis of the NPI-NH results showed a similar pattern of improvement, and the improvement was significant (beta = -.886, p+.001, 95% CI: -1.411 to -.361). The decreases in the NPI total scores appeared to be primarily due to improvement in delusions, hallucinations, apathy, irritability and aberrant motor behaviour.

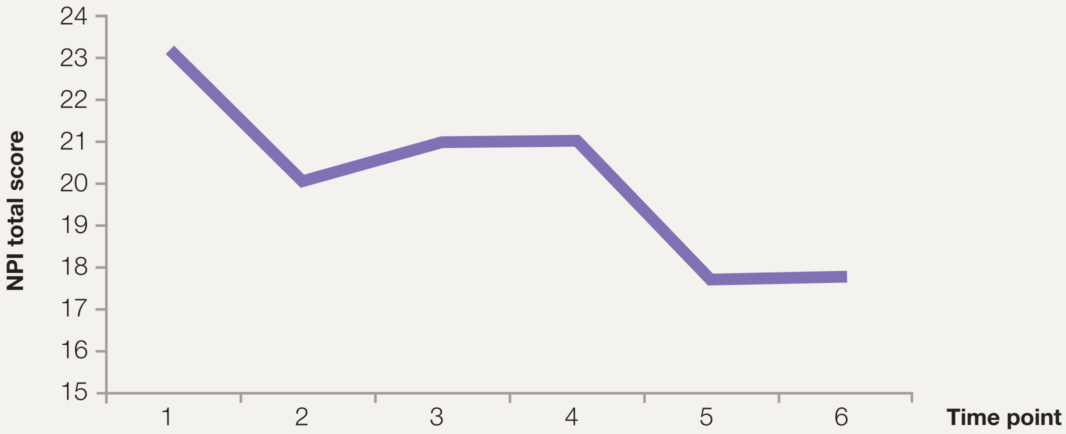
Changes in the Cornell Scale

Depression, as assessed by the Cornell Depression Rating Scale, was reduced significantly over the course of the project (beta + -2.329, p +.002, 95%CI -3.777 -.882)

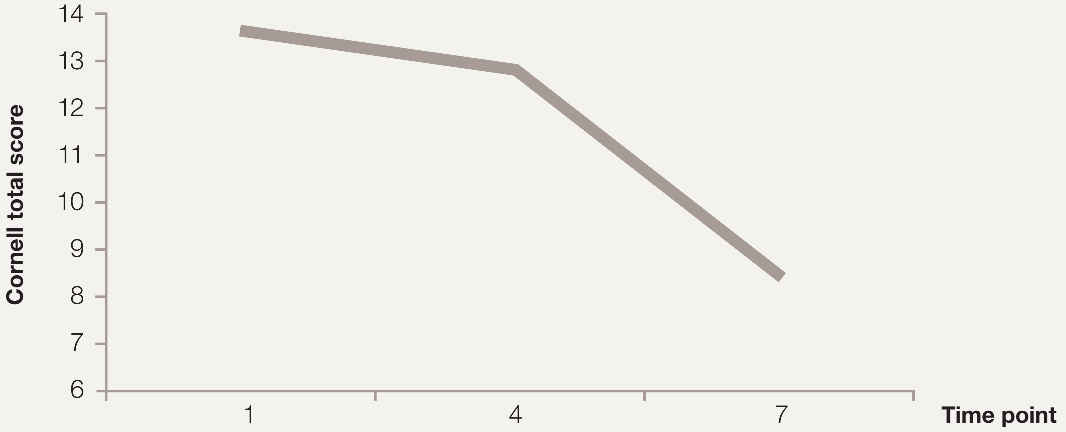
Graph 1: Change in CMAI Scores



Graph 2: Changes in NPI Scores



Graph 3: Changes in Cornell Depression Rating Scale



Impact on staff knowledge and attitudes

Two days of training were provided in all facilities and a total of 171 staff participated: 34 registered nurses, 19 enrolled nurses and 96 personal care assistants. A 29 item questionnaire was administered at the beginning and end of the training to assess knowledge on the causes of behaviours of concern and approaches to reducing them. The level of improvement of knowledge was highly significant between pre and post training, indicating an improvement for all staff attending training.

Staff strain was measured during the training and again at the end of the interventions, using the Staff Strain Scale.[33] On the advice of the Strain Scale authors, the two strongest sub-scales were used. These sub scales provided information on the level of strain, and the frequency of the strain, associated with difficulties in understanding the resident and empathising with their suffering. 147 staff completed the scales at baseline and 43 at completion of the project. There was a trend towards reduction in strain.

Perhaps more instructive was data collected though staff focus groups, conducted by an independent evaluator. The evaluators report included staff comments about a number of areas of change:

What was the Participants' understanding of what the project aimed to achieve?

Staff stated the project was about "looking at the person behind the behaviours." Across the facilities most participants had a relatively clear idea of what the parameters of the project were, although the detail and expression of this varied.

Most understood that the emphasis was on improving the quality of life of those people living with dementia and more behaviours of concern.

Many participants made the connection that this was about looking "behind" the behaviours to find the person, with an emphasis on the individualised needs of the person. Quality of life was recognised as an overriding aim and the relationship between that and changing staff attitudes was also acknowledged.

How did knowledge and care practices change?

"I've just learnt to cope with the behaviours because there's a person behind the behaviours." There was unanimous support of the notion of increased knowledge, particularly around dementia, which took place as a consequence of the project.

Even when that response was tempered with "I knew a lot already" it was still acknowledged that "something" had improved in terms of learning outcomes.

Participants indicated that they knew a lot more about dementia and many gave enthusiastic examples of how they could apply that knowledge in practice. A number of participants gave tangible examples of how they had amended their care practices to illustrate their learning and change in attitudes and practice.

Staff recognised positive changes in high level emotional skills such as tolerance, patience and understanding, whilst many articulated that their work was no longer as stressful as a consequence of their learning from the project.

Staff talked a lot about feeling calmer around residents and indicated that there was a normalisation of their feelings around some more behaviours of concern. The power of being able to take a step back and regain some objectivity was articulated. There was widespread understanding by staff that care was now more people focussed.

Staff indicated that they had greater respect for their residents as a consequence of knowing more about people's individual stories and life histories. In general there was a clear indication that participants were aware of a direct link between increased knowledge (via the dementia education two day workshops and the Mentoring sessions) and the application of that knowledge to improved care practices.

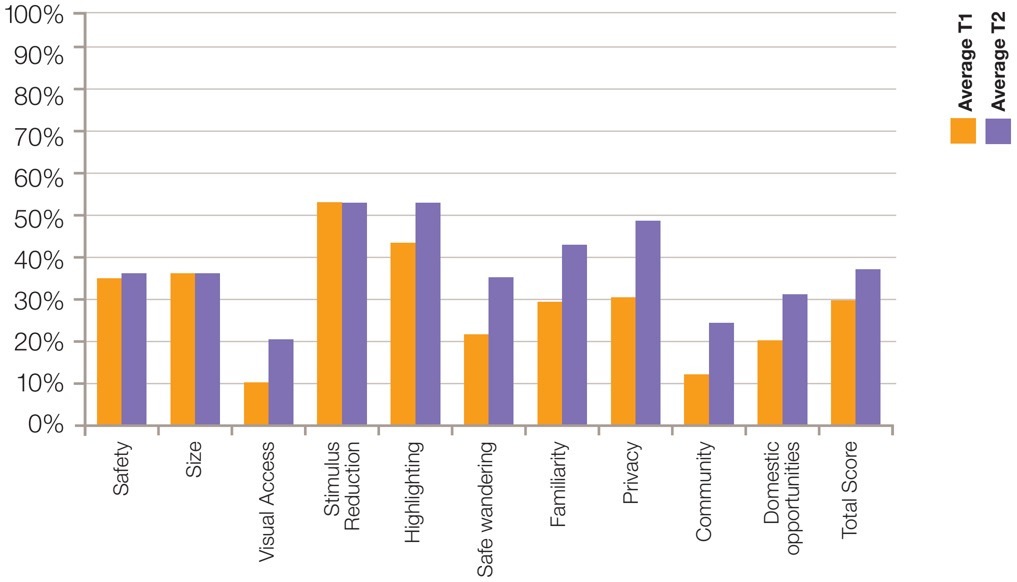
A number of participants identified the significance of pain as a precursor of changing behaviours in their residents. There were a number of specific case examples given of the impact of pain control on behaviour. The importance of good pain management is a message which will stay with many of them for a long time. "But when you realise how many things are wrong with him you understand that he's actually in pain 24 hours a day, and yes, I'm sure I'd be angry too if I was in pain and feeling unwell."

Additionally a number of participants referred to the very practical based skills (for example, basic urine sample testing) that they had developed to assist them to identify and treat delirium. "I now have the confidence to use small steps to get great results."

Impact on the environment

All seven facilities were scored on the Environmental Assessment Tool (EAT) before and after the program The higher the percentage score, the better. Key aspects of the physical envronment improved considerably, even in those facilities where budget was limited and changes were small. While it is difficult to quantify the effects of these improvements, the research basis of the EAT and the changes advised by the project architect suggest that these improvements will reduce overstimulation, confusion and feelings of insecuity. In addition changes will increase helpful prompting, opportunities for socialisation and time spent outdoors or in meaningful activity.

Graph 4: Changes in the before and after EAT scores



Impact on families

Three foundational family support groups were run in six of the facilities (one facility had no family members who wished to be involved). The difficulty of involving families in the care of residents was a theme that emerged from the staff focus groups and was illustrated by the low rate of attendance at the family groups. This project did not overcome the general reluctance of families to be involved nor meet the high expectations of the families who were involved, however the independent evaluator reported that families carers reported improvements in the care of residents over the course of the project.

Economic impact

As mentioned before, the purpose of this project was never financial. We intended to improve quality of life, not income. For this reason initial expenditure was necessary. In particular, staff training, backfill for handovers, the case conferences led by the Mentors and alterations to the physical environment all cost money.

However, we would argue that in the long term, the changes will pay for themselves. In an industry where annual staff attrition rates are on average 25%[34] in part due to burnout and staff dissatisfaction, reducing turnover by supporting and encouraging staff through Mentoring and targeted training can save a facility considerable cost. Similarly, while freeing up a staff member to interact with family will cost an extra few hours per week, this is a minimal outlay compared to the costs associated with an official complaint due to lack of communication and understanding between staff and family. Family involvement can improve life for the residents and provide helpful input for the staff as well as saving time and money.

Finally, the reduction in behaviours and attendant Workplace Health and Safety risks are worthwhile from the financial point of view as well as improving quality of life. In particular, aggressive behaviour by residents puts staff other residents and themselves at risk of injury.

Following up after the end of the project we received anecdotal reports of noticeable drops in referrals from participating facilities to Dementia Behaviour Management Advisory Services and other tertiary behaviour management services. While we have no empirical evidence for this particular outcome, it appears that positive results from this project have been sustained.

Evaluation Tools

The use of reliable evaluation tools is necessary to work out if your intervention is having the desired effect. Reliable tools are those which measure what they are actually intended to measure (not another unintended variable) and are strong enough to yield the same results when two or more different staff conduct the same assessment.

For this project we chose a variety of tools that are well regarded in the literature. The purpose of these tools was to systematically evaluate if we were making a positive difference in reducing behaviours of concern and improving levels of staff confidence, while reducing stress.

Using these evaluation tools together with the strategies described in this Toolkit will provide you with a comprehensive basis for evidence based, results-focused continuous improvement activities.
Full references are given below.

Environment: The Environmental Assessment Tool or "EAT", described in section 1 on the Environment.

Behaviour and its impact: We used three scales:

- the *Cohen-Mansfield Agitation Inventory* (CMAI) which measured how often 29 common *behaviours of concern* occurred;[35]
- the *Neuropsychiatric Inventory-Nursing* Home version (NPI-NH) which measures the how often certain psychiatric symptoms occur, and the amount of distress that these symptoms cause;[36]
- the *Cornell Scale for Depression in Dementia* which now forms part of the Australian Government's Department of Health and Ageing's Aged Care Funding instrument.[37]

Staff stress: was measured by the *Staff Strain Scale*. This scale is an adaptation of a Scandinavian scale, specifically targeted at measuring strain in direct care staff in aged care facilities. This scale is currently undergoing validation in Australia.[38]

Family Perceptions: were measured using *the Family Perceptions of Caregiving Role* (FPCR)[39] scale, developed by Maas and Buckwalter (1990). This scale is designed to measure the feelings of family members about the level of care received by their relative, as well as their own responses to the changes in their relative's situation.

The scales below have been reproduced with the permission of the authors.

We also used qualitative measures in the project, including Focus Group discussions with facility staff and interviews with managers. These discussions and their outcomes are described in the full project report.

Scales: Cohen Mansfield Agitation Index

Cohen-Mansfield Agitation Inventory (CMAI) Instructions

What is it?

The CMAI measures how often residents display 29 common behaviours of concern. The authors refer to these behaviours as 'agitation'. They define agitation as inappropriate verbal, vocal or physical activity that does not directly result from the needs or confusion of the individual. Agitated behaviour is always socially inappropriate and can manifest in three ways:

- It may be abusive or aggressive behaviour
- It may be *appropriate* behavior performed with *inappropriate* frequency i.e. repeated questioning
- It may be *appropriate* behaviour in an *inappropriate* situation i.e. taking clothes off in the activity room.

How does the CMAI work?

The CMAI lists 29 different behaviours of concern in the left hand column. Over the page are detailed descriptions of each of the 29 behaviours. Read these so you are familiar with the behaviours. Note that each behaviour is actually a group of behaviours and if your resident has a related behaviour, but not exactly as described on the form, you can add it to the category. For example if the resident 'squeaks' and the behaviour is not listed you can add it to the category of 'making strange noises' (12).

Do not try to judge if the behaviour can be explained or not, just rate the frequency of occurrence. The right hand columns provide spaces to note how often these behaviours occur, using the categories of:

- Never
- Less than once per week
- 1-2 times per week
- Several times a week
- Once or twice per day
- Several times per day
- Several times per hour

Ratings rely on careful observation of the resident over a two-week period prior completing the survey. The staff member responsible for filling out the form will need to liaise with staff on the other two shifts to give reliable data about the behaviours over the 24 hour period.

To complete the form all you need to tick the box to show the frequency of each behaviour. Don't forget to write the resident's name on the form and date it.

Using the tools and the strategies in this Toolkit will provide you with a basis for evidence based, results-focused, continuous improvement activities.

Detailed description of behaviours:

1. **Pacing and aimless wandering** – constantly walking back and forth, including when in a wheelchair. Does not include purposeful walking.
2. **Inappropriate dressing/disrobing** – putting on too many clothes, or wrongly (ie pants on head), taking off clothes in public.
3. **Spitting (including while eating)** – spitting on floor, people etc. Does not include uncontrollable salivating, spitting into tissue, toilet or onto ground outside.
4. **Cursing or verbal aggression** – swearing, obscene language, unkind speech, criticism, verbal anger. Does not include unintelligible noises (instead rated under screaming/strange noise).
5. **Constant unwarranted request for attention or help** – verbal or non verbal unreasonable nagging, pleading, demanding.
6. **Repetitive sentences or questions** – repeating the same sentence or question, addressing a particular person or no one.
7. **Hitting (including self)** – physical abuse, striking or pinching others, banging self/furniture.
8. **Kicking**- striking forcefully with feet at people or objects.
9. **Grabbing onto people or things inappropriately** – snatching, seizing roughly, taking firmly.
10. **Pushing** – forcefully thrusting, shoving, moving to putt pressure against another person.
11. **Throwing things** – hurling objects, violently tossing objects up in the air, tipping off surfaces, flinging, dumping food.
12. **Making strange noises** – including crying, weeping, moaning, weird laughter, grinding teeth- does not include intelligible words.
13. **Screaming** – shouting, piercing howls, making loud shrills.
14. **Biting** – chomping, gnashing, gnawing either others or self.
15. **Scratching** – clawing, scraping with fingernail self/ others.
16. **Trying to get to a different place** – inappropriately entering or leaving a place - ie get out of the building, off property, sneaking out of a room, into locked areas, trespassing into offices other residents rooms etc…
17. **Intentional falling** – purposefully falling onto the floor- from wheelchair, chair or bed.
18. **Complaining** – whining about self, pain, personal gripes, the environment or others.
19. **Negativism** – bad attitude, nothing is right, doesn't like anything. Does not include overt verbal anger (that is verbal aggression).
20. **Eating or drinking inappropriate substances** – putting into mouth or trying to swallow non edible foodstuffs.
21. **Hurting self or others** – burning, cutting, touching with harmful objects self or others.
22. **Handling things inappropriately** – picking up things that don't belong to them, rummaging through drawers, moving furniture, playing with food, fecal smearing.
23. **Hiding things** – putting objects out of sight, under or behind something.
24. **Hoarding things** – putting many items in purse, pockets or drawers, keeping too many of 1 thing (does not include specific collections ie stamps).
25. **Tearing things or destroying property** – shredding, ripping, breaking, stomping.
26. **Performing repetitious mannerisms** – ie patting, tapping, rocking self, fiddling with something, rubbing self or object, sucking fingers, taking shoes on and off, picking things, picking up imaginary things from the floor, manipulation of nearby objects in a repetitious way.
27. **Making verbal sexual advances** – sexual propositions, sexual innuendo or dirty talk.
28. **Making physical sexual advances or exposing genitals** – touching someone in an inappropriate sexual way, rubbing genital area, inappropriate masturbation (when not alone or in own room or bathroom), unwanted fondling or kissing.
29. **General restlessness** – fidgeting, always moving around in seat, getting up and sitting down repeatedly, inability to sit still.

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[30] Cohen-Mansfield, J., Marx, M. S., & Rosenthal, A. S. (1989). A description of agitation in a nursing home. Journal of Gerontology: Medical Sciences, 44(3), M77-M84.

[31] Wood, S., et al., (2000) The use of the neuropsychiatric inventory in nursing home residents: Characterization and measurement. The American Journal of Geriatric Psychiatry, 8(1): p. 75.

[32] Alexopoulos, G.S., Abrams, R. C., Young, C., & Shamoian, C. A., (1988) Cornell Scale for Depression in Dementia. Biological Psychiatry,. 23(3): p. 271-284.

[33] (Edberg and Bird 2007, scale under development)

[34] Martin, B., & King, D. (2008). Who cares for older Australians. Adelaide: National Institute of Labour Studies.

[35] This scale was developed by Jiska Cohen-Mansfield. We recommend that you consult the manual prior to use. The manual can be found at http://www.dementia-assessment.com.au/symptoms/cmai_manual.pdf.

[36] We have not included the NPI-NH, for copyright reasons.

[37] A detailed manual for using the Cornell Scale can be found on the Australian Government Department of Health and Ageing website, at http://www.health.gov.au/internet/publications/publishing.nsf/Content/ageing-rescare-natframe.htm~ageing-rescare-natframe08.htm

[38] Edberg A.K., Bird M., Strains in Dementia Care Scale (Australian version in development, unpublished at time of writing.)

[39] Developed by the Family Involvement in Care research team, Meridean L. Maas, PhD, RN, FAAN, Principal Investigator, College of Nursing, The University of Iowa. The Family Involvement in Care research was funded by the U.S. National Institutes of Health, National Institute of Nursing Research.

Cohen-Mansfield Agitation Inventory

A seven point rating scale for assessing the frequency with which people show certain behaviours. Rate each descriptor from 1-7. The scale takes 10-15mins to complete.

1 = never
2 = less than once per week
3 = 1-2 per week
4 = several times per week
5 = 1-2 per day
6 = several times per day
7 = several times per hour

Behaviour		**Rating**						
1.	Pace, aimless wandering	1	2	3	4	5	6	7
2.	Inappropriate dress or disrobing	1	2	3	4	5	6	7
3.	Spitting (include at meals)	1	2	3	4	5	6	7
4.	Cursing or verbal aggression	1	2	3	4	5	6	7
4.	Constant unwarranted request for attention or help	1	2	3	4	5	6	7
5.	Repetitive sentence or questions	1	2	3	4	5	6	7
6.	Hitting (include self)	1	2	3	4	5	6	7
7.	Kicking	1	2	3	4	5	6	7
8.	Grabbing onto people	1	2	3	4	5	6	7
9.	Pushing	1	2	3	4	5	6	7
10.	Throwing things	1	2	3	4	5	6	7
11.	Strange noises (weird laughter or crying)	1	2	3	4	5	6	7
12.	Screaming	1	2	3	4	5	6	7
13.	Biting	1	2	3	4	5	6	7
14.	Scratching	1	2	3	4	5	6	7
15.	Trying to get to a different place (e.g. out of the building)	1	2	3	4	5	6	7
17.	Intentional falling	1	2	3	4	5	6	7
18.	Complaining	1	2	3	4	5	6	7
19.	Negativism	1	2	3	4	5	6	7
20.	Eating/drinking inappropriate substances	1	2	3	4	5	6	7
21.	Hurt self or others (cigarette, hot water etc.)	1	2	3	4	5	6	7
22.	Handling things inappropriately	1	2	3	4	5	6	7
23.	Hiding things	1	2	3	4	5	6	7
24.	Hoarding things	1	2	3	4	5	6	7
25.	Tearing things or destroying property	1	2	3	4	5	6	7
26.	Performing repetitious mannerisms	1	2	3	4	5	6	7
27.	Making verbal sexual advances	1	2	3	4	5	6	7
28.	Making physical sexual advances	1	2	3	4	5	6	7
29.	General restlessness	1	2	3	4	5	6	7

Cohen-Mansfield, J., Marx, M. S., & Rosenthal, A. S. (1989). A description of agitation in a nursing home. Journal of Gerontology: Medical Sciences, 44(3), M77-M84.

Cornell Scale

Instructions: This scale should be completed on all residents being assessed. The ratings should be based on symptoms and signs occurring during the week prior to completion. No score should be given if symptoms result from physical disability or illness.

	(Please circle your responses)	Unable to rate	Absent	Mild or only happens from time to time	Severe
Mood	1. **Anxiety:** *anxious expression, ruminations, worrying*	A	0	1	2
	2. **Sadness:** sad expression, sad voice, tearfulness	A	0	1	2
	3. **Lack of reactivity to pleasant events:** does not cheer up when offered pleasant activities	A	0	1	2
	4. **Irritability:** easily annoyed, short tempered	A	0	1	2
Behavioural Disturbance	5. **Agitation:** restlessness, hand-wringing, hair-pulling	A	0	1	2
	6. **Slowness:** slow movements, slow speech, slow reactions	A	0	1	2
	7. **Multiple physical complaints:** complains about physical health more than is reasonable (score 0 if gastro-intestinal symptoms only	A	0	1	2)
	8. **Loss of interest:** less involved in usual activities (score 1 or 2 only if change occurred acutely, ie in less than 1 month)	A	0	1	2
Physical signs	9. **Appetite loss:** eating less than usual	A	0	0	1
	10. **Weight loss:** (score 2 if greater than 2.5 kg in 1 month)	A	0	1	2
	11. **Lack of energy:** fatigues easily, unable to sustain activities (score only if change occurred acutely, ie in less than 1 month)	A	0	1	2
Changes in daily/ nightly mood and behaviours	12. **Changes of mood:** mood changes as the day progresses with symptoms worse in morning	A	0	1	2
	13. **Difficulty falling asleep:** later than usual for this individual	A	0	1	2
	14. **Multiple awakenings during sleep:** wakes up more often than is usual for this individual	A	0	1	2
	15. **Early morning awakening:** earlier than usual for this individual	A	0	1	2
Ideational Disturbance	16. **Suicide:** feels life is not worth living, has suicidal wishes or makes suicide attempt	A	0	1	2
	17. **Poor self esteem:** self-blame, self-depreciation, feelings of failure	A	0	1	2
	18. **Pessimism:** anticipation of the worst, thinks things are always going to go wrong	A	0	1	2
	19. **Depressing delusions:** delusions of poverty, illness or loss. Cannot be convinced that they are not poor or ill or that they have lost something or somebody.	A	0	1	2

Total = Add all 1s + 2s in the shaded area

Alexopoulos, G.S., Abrams, R. C., Young, C., & Shamoian, C. A., (1988) Cornell Scale for Depression in Dementia. Biological Psychiatry,. 23(3): p. 271-284.

Strains in Dementia Care

(27-item version 2012)

Section 1 –
Situations, thoughts and feelings in the care of persons with dementia

The following statements express situations and thoughts or feelings which can arise when caring for people with dementia. We want to find out how often you encounter these situations and feelings and, when they occur, how much stress they cause you.

Please mark the box that best correspond to your experience.

Situation, thought or feeling	How frequently do you experience these situations, thoughts or feelings?				When they do occur, how much stress does it cause you?			
	Never	Some-Times	Quite Often	Very often	None	Mild Stress	Moderate stress	High Stress
1. I feel that my work is not valued by others.	☐	☐	☐	☐	☐	☐	☐	☐
2. I find it difficult to understand what residents/clients are experiencing or feeling.	☐	☐	☐	☐	☐	☐	☐	☐
3. I want to do much more for residents/clients than my employers allow me to.	☐	☐	☐	☐	☐	☐	☐	☐
4. My employers do not appreciate the work I am doing.	☐	☐	☐	☐	☐	☐	☐	☐
5. I have difficulty understanding what residents/clients are trying to communicate.	☐	☐	☐	☐	☐	☐	☐	☐
6. I have difficulty understanding the needs of residents/ clients.	☐	☐	☐	☐	☐	☐	☐	☐
7. I find it difficult to know what is the best for residents/clients.	☐	☐	☐	☐	☐	☐	☐	☐
8. I worry I might upset or hurt a resident/client because I do not understand his or her needs.	☐	☐	☐	☐	☐	☐	☐	☐
9. When a resident/client dies or has to move I feel as though I have lost a relative or close friend.	☐	☐	☐	☐	☐	☐	☐	☐
10. I can not understand why residents/clients behave the way they do.	☐	☐	☐	☐	☐	☐	☐	☐
11. I find it difficult to explain to residents/ clients what is happening in situations which may upset them (e.g. showering, bathing or toileting).	☐	☐	☐	☐	☐	☐	☐	☐

Edberg A.K., Bird M., Strains in Dementia Care Scale (Australian version in development, unpublished at time of writing.)

Situation, thought or feeling	**How frequently do you experience these situations, thoughts or feelings?**				**When they do occur, how much stress does it cause you?**			
	Never	Some-Times	Quite Often	Very often	None	Mild Stress	Moderate stress	High Stress
12. I have to balance the needs of a resident/client against the needs or demands of his or her family.	☐	☐	☐	☐	☐	☐	☐	☐
13. I have to balance the needs of a resident/client against the needs or demands of other residents/clients.	☐	☐	☐	☐	☐	☐	☐	☐
14. I have to prioritise on the basis of urgency rather than fairness or the needs of residents/clients.	☐	☐	☐	☐	☐	☐	☐	☐
15. I feel the residents/clients are highly dependent on me.	☐	☐	☐	☐	☐	☐	☐	☐
16. I wish I knew more about residents/clients so that I could understand them better.	☐	☐	☐	☐	☐	☐	☐	☐
17. I can not stop thinking about residents/clients when I am away from work.	☐	☐	☐	☐	☐	☐	☐	☐
18. I see other staff behaving towards a resident/client in a way which shows they do not understand the effects of dementia.	☐	☐	☐	☐	☐	☐	☐	☐
19. The families of residents/clients do not seem to understand how difficult it is to care for their relative.	☐	☐	☐	☐	☐	☐	☐	☐
20. Residents/clients resist the care I want to/need to provide.	☐	☐	☐	☐	☐	☐	☐	☐
21. I have to balance the safety of a resident/client against their quality of life e.g. using restraint).	☐	☐	☐	☐	☐	☐	☐	☐
22. I see that a resident/client is suffering.	☐	☐	☐	☐	☐	☐	☐	☐
23. Residents/clients do not receive the care I feel they are entitled to.	☐	☐	☐	☐	☐	☐	☐	☐
24. I see how the family of a resident/client is suffering.	☐	☐	☐	☐	☐	☐	☐	☐
25. I see residents/clients being mistreated by their family.	☐	☐	☐	☐	☐	☐	☐	☐
26. I see other staff treating a resident/client badly.	☐	☐	☐	☐	☐	☐	☐	☐
27. Other staff change what I have tried to do for a resident/client.	☐	☐	☐	☐	☐	☐	☐	☐

Edberg A.K., Bird M., Strains in Dementia Care Scale (Australian version in development, unpublished at time of writing.)

Strains in Dementia Care

(27-item version 2012)

Section 2 – Daily emotions

During a day of work how often do you experience the following emotions?
Please mark the box that best correspond to your experience.

	Never					All the time
Powerlessness	☐	☐	☐	☐	☐	☐
Satisfaction	☐	☐	☐	☐	☐	☐
Sadness	☐	☐	☐	☐	☐	☐
Frustration	☐	☐	☐	☐	☐	☐
Fear	☐	☐	☐	☐	☐	☐
Joy/happiness.	☐	☐	☐	☐	☐	☐

Thank you for taking the time to answer the questions!

Edberg A.K., Bird M., Strains in Dementia Care Scale (Australian version in development, unpublished at time of writing.)

Family Perception of Care-giving Role (FPCR)

Family Member's I.D. # Date:

Thank you for completing the Family Perceptions of Care-giving Role.
This Survey will take about 15-20 minutes to complete.

DIRECTIONS: Each of the statements in this questionnaire describes something about your role in the care of your family member in residential care. You are asked to indicate your feelings about each statement in terms indicating how much you agree or disagree.

A rating of **1 means that you "strongly disagree"** with the statement; a rating of **7 means that you "strongly agree"** with the statement.

There are no right or wrong answers. Please respond based on your feelings.

Sample question:	Strongly disagree					Strongly agree	
I feel like I am welcome in the facility each time I visit.	1	2	3	4	5	6	7

Please Return this questionnaire to your mentor , in the attached envelope.

We greatly appreciate your assistance with the Encouraging Best Practice in Residential Aged Care project.

		STRONGLY DISAGREE						STRONGLY AGREE
1.	I feel like I have to be careful about how I make suggestions or requests about my relative's care or staff will think I am interfering	1	2	3	4	5	6	7
2.	I feel like an outsider in the care of my relative	1	2	3	4	5	6	7
3.	I feel that I have control over the care my relative receives	1	2	3	4	5	6	7
4.	Staff listen to my directions for my relative's care, but ignore them if they choose	1	2	3	4	5	6	7
5.	It is clear that staff have the real say about what care will be provided and how	1	2	3	4	5	6	7
6.	Things that I see as important in my relative's care staff often see as trivial or inconvenient	1	2	3	4	5	6	7
7.	Staff are most concerned about rules, routines and efficiency while I am most concerned about caring for my relative as an individual	1	2	3	4	5	6	7
8.	No major changes are made in the care of my relative without my approval	1	2	3	4	5	6	7
9.	I feel stressed between trying to give to my loved one in care as well as to other family responsibilities, job, etc	1	2	3	4	5	6	7
10.	I feel guilty about my interactions with my loved one who is ill	1	2	3	4	5	6	7
11.	I feel that I don't do as much for my loved one in the nursing home as I could or should	1	2	3	4	5	6	7
12.	I feel that in the past, I haven't done as much for my loved one who is now in the nursing home as I could or should	1	2	3	4	5	6	7
13.	I feel nervous or depressed about my interactions with my loved one in the nursing home	1	2	3	4	5	6	7
14.	I feel comfortable in my interactions with my loved one	1	2	3	4	5	6	7

Developed by the Family Involvement in Care research team, Meridean L. Maas, PhD, RN, FAAN, Principal Investigator, College of Nursing, The University of Iowa. The Family Involvement in Care research was funded by the U.S. National Institutes of Health, National Institute of Nursing Research.

		STRONGLY DISAGREE						STRONGLY AGREE
15.	I feel that my health has suffered because of my involvement with my loved one who is in care.	1	2	3	4	5	6	7
16.	When family and staff have different ideas about care the disagreements are negotiated and resolved.	1	2	3	4	5	6	7

Family caregivers of people in care sometimes feel that they lose important things in life because of their relative's illness. To what extent do you agree or disagree that **you personally have lost** the following?

17.	Having someone who really knew you well?	1	2	3	4	5	6	7
18.	The practical things he/she used to do for you?	1	2	3	4	5	6	7
19.	A chance to do some of the things you planned?	1	2	3	4	5	6	7
20.	Contact with other people?	1	2	3	4	5	6	7

Family members may feel sorrow over the illness of their loved one and the changes that the illness has made in their lives: To what extent do you agree or disagree that you **feel sorrow** over:

21.	Loss of companionship?	1	2	3	4	5	6	7
22.	Other's inability to know how your loved one used to be?	1	2	3	4	5	6	7
23.	Lack of privacy with your loved one?	1	2	3	4	5	6	7
24.	Inability to control how your loved one is cared for?	1	2	3	4	5	6	7
25.	Loss of your role as primary caregiver of your loved one?	1	2	3	4	5	6	7

Here are some thoughts and feeling that people sometimes have about themselves when they are caregivers of a relative who is ill. How much do you agree or disagree that each statement describes your thoughts about your care giving?

26.	Wish you were free to lead a life of your own?	1	2	3	4	5	6	7
27.	Feel trapped by your relative's illness?	1	2	3	4	5	6	7
28.	Wish you had more time to spend with friends?	1	2	3	4	5	6	7
29.	Feel like you have lost your relative but still have the same role responsibilities as if you hadn't?	1	2	3	4	5	6	7

Thank you for filling out the questionnaire!

Research Staff I.D. # Date:

Background Information:

1. What is your relationship with your resident? Eg. Spouse, sibling, adult child

2. Where you the resident's primary care giver before they entered care?

a. If yes, how long were you the primary care giver? yrs mnths

Developed by the Family Involvement in Care research team, Meridean L. Maas, PhD, RN, FAAN, Principal Investigator, College of Nursing, The University of Iowa. The Family Involvement in Care research was funded by the U.S. National Institutes of Health, National Institute of Nursing Research.

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The Dementia Centre

Greenwich
Pallister House, Greenwich Hospital
97-115 River Road, Greenwich NSW 2065
PO Box 5084, Greenwich NSW 2065

Hammondville
Judd Avenue, Hammondville, NSW 2170

P +61 2 8437 7355 • **F** +61 2 9825 1044 • **E** dementia@hammond.com.au
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