BETTER FOR EVERYONE

Tools for managers, staff and families

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HammondCare
An independent Christian charity

About The Dementia Centre and Better for Everyone

HammondCare is an independent Christian charity which provides health and aged care services to people across New South Wales. Our passion is improving quality of life for people in need. We serve people with complex health or aged care needs, regardless of their circumstances. Since the 1990's HammondCare has become internationally recognised as a leader in the field of dementia specific aged care.

The Dementia Centre, HammondCare, supports excellence in dementia care by providing research, education, conferences and consultancy services, internally and to external organisations and groups.

Better for Everyone was originally funded by the Australian Government Department of Health, under the Encouraging Better Practice in Aged Care (EBPAC) initiative, as 'Reducing behaviours of concern in residential aged care by working with staff, families and the physical environment.' This toolkit was developed by Meredith Gresham and Rebecca Forbes at the Dementia Centre, HammondCare, from the findings of the project. The dissemination of the resource was funded by a grant from The J.O. and J.R. Wicking Trust, which is managed by ANZ Trustees.

The EBPAC programme aims to improve the level of practice in aged care by supporting the uptake of existing evidence and translating it into effective approaches for staff to use in their everyday practice.

The major organisational partners in the project were HammondCare and Uniting Aged Care Victoria and Tasmania. An independent evaluation was conducted by the Dementia Collaborative Research Centre at the University of New South Wales. The evaluation was led by Professor Henry Brodaty.

The project team comprised of:

Meredith Gresham – Senior Dementia Consultant, Research and Design, at The Dementia Centre, HammondCare. Meredith managed much of the day to day running of the project, including support of the mentors, coordination of the evaluation and providing specialist input to the family support activities.

Richard Fleming – was Director of the Dementia Centre, HammondCare, until December 2010. Richard provided leadership and guidance for the project overall.

Kirsty Bennett – Architect, and Manager of Environmental Design Education Services at the NSW/ACT Dementia Training Study Centre. Kirsty undertook the environmental audits, provided the aged care homes with advice on, and support with, environmental modifications and monitored their implementation.

Mike Bird – Former Director of the Greater Southern Area Health Services Aged Care Evaluation Unit. Mike provided specialist advice and training on the mentoring process.

In addition, the staff education, mentoring and family support were provided by Sue Aberdeen, Sue Lenon and Patricia Murdoch; three registered nurses with a great deal of experience in the care of people with dementia and experts in educating, supporting and leading staff in aged care homes.

We'd like to thank Natalie Duggan for her assistance in the preparation of training materials.

Finally, we would like to acknowledge the valuable contribution of the managers, staff, families and residents of the aged care homes who took part in the project.

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DC Dementia Centre

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Contents

BETTER FOR STAFF

Our experiences

The wellbeing of residents is the most important aim for any aged care home. 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, *distressed behaviour*, teamwork and useful communication strategies.

Responding appropriately to *distressed behaviour* 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 distressed behaviour.

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 distressed behaviour 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 distressed behaviour. The meetings were aimed at helping staff understand their own feelings, the feelings of the people with distressed behaviour and how they could use an understanding of these feelings to work in a different way to reduce the distressed behaviour. 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 his or 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 aged care home. 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

In some aged care homes there were some difficulties finding a private space conducive to sharing feelings and experiences. In one home sessions were conducted from time to time in 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.

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

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 our project both roles were 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 distressed behaviour. 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 distressed behaviour 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 our 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 aged care home 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 him or 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.

BETTER FOR FAMILIES

Family support – evidence from research

Many aged care homes 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 home 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 changed behaviours can also be immensely changed 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 aged care home has many benefits. It will help the families to understand the care their relative is receiving and to learn from other relatives going through the same 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.

NB: 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 aged care home, 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 aged care home.

The involvement of family is universally regarded as best practice in the management of residents who display changed behaviours.[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 aged care home has many benefits, including helping the families to understand the care their relative is receiving.

BETTER DESIGN

Our experiences

This section explains the process we undertook to evaluate the existing environment at each aged care home 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 aged care home and think about opportunities for improvement.

Background

The project began with the selection of the seven aged care homes across New South Wales and Victoria. The aged care homes were chosen because they represented typical, residential care homes. They were not new, had no strong links with specialised services and five of the seven aged care homes 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 aged care homes there was probably one quite similar to yours.

Process

The first step we took was an environmental audit of each aged care home. 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 aged care home whose behaviours were causing concern. There was a wide range of changed behaviours across the aged care homes. One aged care home had few active distressing behaviours (e.g. aggression) but several very withdrawn residents. Other homes 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 aged care home.

Lessons learnt

- The process of introducing environmental changes into the seven aged care homes 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 an aged care home 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 18 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!

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 aged care home 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 aged care home. 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 distressed behaviours, 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 aged care homes 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 three time points, using the Cornell Depression Rating Scale (CDRS).[32]

The baseline, or pre-intervention assessment showed that 48% of residents had major symptoms of depression. The amount and type of overt distressed behaviours (e.g. agitation or aggression) as measured by the CMAI, were significantly different between aged care homes; the residents in the project in some homes were significantly more agitated than those in others; however the changes that took place in all aged care homes 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 CDRS, was reduced significantly over the course of the project (beta + -2.329, p +.002, 95% CI: -3.777 -.882)