THE QUEEN'S NURSING INSTITUTE SCOTLAND

Promoting Excellence in Community Nursing across Scotland

Telling the Story

Impacts of the Delivering Dignity Programme in Scotland

Qnis THE QUEEN'S NURSING INSTITUTE SCOTLAND

Burdett Trust for Nursing

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The generous funding from The Burdett Trust for Nursing has enabled the work, and the extra miles walked by the participants have led to the remarkable results this publication describes.

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Introduction

Undignified care leaves people feeling less valued, somehow less human. The Queen's Nursing Institute Scotland (QNIS) and The Burdett Trust for Nursing are partners in promoting care that respects people's individuality, independence and dignity. This relates particularly, but not exclusively, to the care of older people, many of whom can find themselves in vulnerable situations over short or long periods in which they are highly dependent on the people who care for them.

Older people are entitled to expect those carers to meet their physical, psychological, social and spiritual needs in a way that respects their dignity and individuality. But the report of the independent Commission on Dignity in Care, *Delivering Dignity*, spells out in chastening detail how many older people are being failed by the systems that are supposed to protect them. The report calls for "a major cultural shift in the way the system thinks about dignity, to ensure that care is person-centred and not task-focused."

Responding to the Commission report, The Burdett Trust advertised for funding partners to manage a programme of grants focusing on dignity in care. QNIS applied to become a partner, and the Delivering Dignity Programme that resulted in the six projects reported here was launched.

The projects, which were taken forward in diverse areas of Scotland, demonstrate how innovative research can protect and enhance the dignity of older people, including those who are most vulnerable. They show how groups of researchers from different professional backgrounds can collaborate in common cause to make things better for older people and their families. And they confirm that meaningful change isn't necessarily wholesale – people's lives can be improved through small, purposeful steps.

The projects also represent significant steps forward for the teams involved, promoting leadership and research skills and generally expanding research capacity and capability among community nurses. It is worth noting too that while the grants provided by the programme were clearly valued, they were not excessive – the research teams were not enticed to apply by the prospect of lucrative sums of money, but by their passion for the projects and their ongoing commitment to protecting and enhancing the dignity of older people and their families.

We have not tried in this publication to summarise the underpinning theories, methods, results and outcomes of the projects. Each produced a comprehensive report, and I recommend that you access and read these to gain a full understanding of how the projects were designed, delivered and evaluated.[1]

Here, we are focusing on impacts – what the projects have meant to older people, their families and staff – through the words of some of the people who delivered them. The stories they tell are engaging, compelling and inspiring. Their areas of focus – telling our life stories, eating and drinking, overcoming sensory impairments, conversing and sharing time, accessing support and advice – are everyday occurrences that provide structure, purpose and pleasure in our lives, but whose accomplishment often presents challenges for older people, families and staff.

The stories also teach us that while realising positive change is challenging – one of the common characteristics of the projects is just how hard the teams, older people, families and staff had to work to implement them – sustainable change is possible when everyone gets on board. Crucially, it was not just staff practices, but also the perceptions and attitudes that underpin them that changed for the better. Even the language used by staff in one of the projects evolved to reflect greater respect for older people's individuality and dignity. All these enhance the prospects of ongoing positive change.

As one of the team leaders says about the project she was part of, "having done the hard yards, we can now celebrate success". I am delighted to share with you the successes the projects achieved, highlighting the positive impacts of adopting approaches that are genuinely "person-centred and not task-focused".

Clare Cable
Chief Executive and Nurse Director
Queen's Nursing Institute Scotland

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[1] You can access the reports at: **www.qnis.org.uk**

Carnbroe Care Centre,
Coatbridge

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Caring conversations

Bringing dignity to everyday practice

Evidence on the importance of human interaction and relationships to delivering dignified and compassionate care is clear. What is much less clear is how processes that promote dignity and compassion can be enacted in everyday practice.

The doctoral thesis of Professor Belinda Dewar of the University of the West of Scotland presents a model for dignified and compassionate care with the idea of "caring conversations" at its heart. The model, which was developed from observing interactions involving staff, patients and families, was used as the centrepiece of a 10-month project that Belinda coordinated, supported by her university colleague Tamsin MacBride. The project actively involved residents, families and staff of Carnbroe Care Centre in North Lanarkshire.

"Caring conversations feature seven key elements – being courageous, connecting emotionally, being curious, considering other perspectives, collaborating, compromising and celebrating," Belinda explains. "Our aim was to test the model in practice and develop education to promote caring conversations with and for the people in the care home."

For Belinda, this short-term project was primarily about translating theories and evidence on promoting dignity into everyday practice.

"Without greater clarity about how to support practitioners to realise aspirations in practice, terms like 'dignity' and 'compassion' will remain little more than words," she says. "They may trip easily off the tongue but will remain elusive in reality, particularly in a health and social care culture dominated by ideas of productivity, efficiency and effectiveness and which promotes quick-fix solutions."

Belinda believes dignified and compassionate care can be taught, but fears that the current focus on mechanistic models of behavioural communication skills fails to address adequately the relationship element that is crucial to its delivery.

"We need education that provides greater emphasis on human relating and acknowledges the common humanity that binds patients, relatives and staff," she says. "This can be achieved through an appreciation of people's connectedness and an emphasis on being with people, rather than doing for them."

The model of caring conversations had not been tested in a care home environment prior to the project. A core team including staff members and residents, with relatives also playing key roles, was assembled and work got underway, as Tamsin MacBride explains.

"We wanted to find out, first of all, what was already working well in the home so we could build on it," she says. "We then looked at how these features related to the caring conversations framework before identifying interventions that would support staff to use the framework in practice."

The team employed different methods to identify what was working well, including direct observation of practice and using creative means of enabling residents' voices to be heard, such as focusing on images and key words that reflect particular emotions they had experienced. The information the team collected was shared with staff so they could jointly envision a way forward.

"The key area staff, residents and families valued was about really getting to know the person well," Tamsin says. "That's not just about what they like in their tea, but being able to pick up little indicators that would suggest something was wrong and making sure the things that bring pleasure and fulfilment to a day are in place. An example of the latter for one particular lady was that she liked to be left alone if she was feeling down – this prompted a lot of reflection and discussion among staff, some of whom had assumed that residents would prefer to have company if they were feeling low."

A positive area of practice identified was the use of person-centred language by staff. "We noticed one individual, for instance, who referred to a resident as 'the lady who likes to be on the move a lot of the time' instead of the 'wanderer', which is a phrase other individuals might sometimes use," Tamsin says. Statements such as this were matched to appealing images and displayed in the home, allowing staff to reflect on their meaning and importance and prompting further discussion about the use of language in the care centre.

A more compassionate, respectful and consensual vocabulary developed as a result, with terms such as "dementia sufferer" being replaced by "a resident who has dementia" and a statement like "we need to enhance compliance" being succeeded by "we need to work with people to foster commitment".

"This is not just about semantics," Tamsin notes. "It represents a very different way of thinking about and delivering care."

Belinda observed that the approach used in the project alongside the caring conversations framework was freeing staff to make changes. "The staff were inquiring into their own practice, finding out what really mattered to them and coming up with their own solutions for change through the use of visual, auditory and other means," she says. "And their commitment was fantastic – on more than one occasion, members of the core team were involved in project work on their days off."

Despite their clear enthusiasm for the approach, some staff found it difficult to describe what the project was really about, which could have presented an impediment to efforts to bring others into common cause. An online resource, which can be found on the My Home Life Scotland website, was developed to explain the thinking underpinning the approach and provide information and tools. "Staff can now go to the resource and say to others 'this is what the project was about, and this is what we're trying to achieve'," Belinda says.

> *"The key area staff, residents and families valued was about really getting to know the person well*

Belinda and Tamsin recognise that this was an ambitious project – the co-coordinators estimate that it probably required double its original anticipated time commitment – but believe the journey has transformed practice.

"Staff created a poem to explain the impact of the project," Tamsin says. "They explain in the poem that they now realise sharing feelings opens up conversations. Exploring feelings can be risky – it takes courage, but staff now understand its power. They have ceased wondering, for example, how they would like to be cared for, and started asking residents how they want to be cared for, understanding the important things that matter to them and making time to ask questions.

"One staff member told us how she used to hide when relatives came into the home," she continues. "Now she goes out to greet them and ask them how they are. Another used to tell people what they were not doing well – now she commends them for what they are doing well. Caring conversations bring ideas like engagement, participation and being heard into reality."

Western Isles Sensory Centre & Community

2

Raising community nurses' awareness of sensory impairment

An educational approach

Sensory impairment, which includes poor sight and hearing loss, can affect any age group, but is more common in later life. As the proportion of older people in Scotland rises, so the prevalence of sensory impairment will also rise.

Any degree of sensory impairment can impact on people's ability to carry out day-by-day tasks and functions – everything from doing the shopping to answering the phone. Impairment also negatively affects people's autonomy and independence by increasing their reliance on community and family support. It can therefore pose a threat to older people's sense of dignity, a fact recognised by the Commission on Dignity in Care for Older People in their report, *Delivering Dignity*, and by the Scottish Government in its strategy on how services can better support people with sensory impairment, *See Hear*.

The project that Dr Annetta Smith of the University of Stirling launched with colleagues from NHS Western Isles and Sight Action, a charity dedicated to making life better for blind and partially sighted people in the Highlands and Western Isles, was therefore timely and relevant.

"The aim was to increase the number of people who benefit from the Western Isles Sensory Centre (WISC) and other specialist services providing visual and/or hearing support by raising awareness of sensory impairment among community nurses," Annetta explains. "It was truly a collaborative venture that involved the university, community nurses and sensory services in the Western Isles pooling their combined expertise to maximise impacts."

WISC, situated in Stornoway, offers a "one-stop-shop" approach to providing advice and services for people with sensory impairments. A previous evaluation of the service showed a high level of user satisfaction, with evidence that interventions had positively enhanced aspects of people's lives. The evaluation also reported, however, a low level of service awareness among the general population and health and social care professionals and recommended that steps be taken to increase this.

The project team developed and delivered training for community nurses, as team member Karen MacLeod, a community staff nurse in NHS Western Isles, explains.

"We weren't trying to make the nurses experts in sensory assessment – it was all about raising awareness of services," she says. "Five training workshops were delivered across the islands, looking at key elements such as the main causes of visual and hearing impairment, the impact on individuals and their carers, and how to refer into the services available in the Western Isles."

The workshops also included sensory impairment simulation exercises. "The simulation exercises included wearing spectacles that mimicked certain sight impairments, and the nurses were asked to perform a few simple daily tasks – doing a shopping list, writing a cheque, sorting out medication," says Karen. "It really helped them to understand what it might be like to have impairments such as cataracts or tunnel vision."

Comparison of participants' awareness of sensory impairment before and after the workshops, based on postal questionnaires and a focus group, revealed greater awareness of the impact of impairment and also indications of a change in attitudes. One participant, for example, said: "I am more sensitive to [people's] needs and will put more input into helping to improve their activities of daily living by advising them and their relatives". Another noted how the awareness generated by the workshops had led to information being spread to other professionals: "I have had a discussion with social care workers and highlighted the awareness of these impairments when dealing with clients and for them to relay any concerns".

Participants were more aware of the struggles people with sensory impairment face and described greater empathy. One said the workshops had "made us strongly aware of how diminished people's lives are when these senses are taken away for them", and another stated how "we sympathised but didn't really have empathy" with people with sensory impairments.

Increased confidence in assessing visual and hearing impairments was evident. One participant said: "I am more likely to spend time discussing with the patient what the problem is and what we can do to help", while another commented: "I now ask direct questions regarding their sight and/or hearing as I feel I now know where to refer them to or what to offer regarding these problems".

Perhaps most striking was increased recognition of the barriers patients face. "The participants recognised that some people may have been living with their impairment for so long that they had come to regard it as 'normal' and would not seek out support, and the people around them often seemed similarly unable to see how services could help," Karen says. "But the nurses understood the profound challenges sensory impairment brings and were determined to be proactive.

"They came up with novel ideas for helping people with sensory impairment to be more aware of services available locally," she continues. "These included providing information through local radio and 'talking papers', which are quite common in rural areas, and raising awareness throughout the primary health care team."

The project also brought benefits to the project team, with Karen finding her involvement particularly motivating.

"My contribution spanned the entire project, including initial preparation of the proposal, development of the research tools, submission for ethical approval, development, delivery and evaluation of the workshops, focus-group interviewing, analysis and final project write-up," she says. "This has given me strong insights into the research journey and has made the idea of being involved in research more appealing and more achievable."

Annetta believes the project helped to demonstrate the importance of raising awareness of sensory impairment and related education not only among nurses, but also across the whole primary care team.

"Community nurses are key, but it's important that awareness is raised throughout the health and social care professions," she says. "The project started off educating community nurses, as they are often well placed to spot disabilities as a result of sensory impairment and identify patients at risk, but the workshops ended up including participants from a wider base, including social work and medical staff.

> “*They came up with novel ideas for helping people with sensory impairment to be more aware of services available locally*

"Health, social and third sector agencies working together through local partnerships can more effectively support the care of older people with sensory impairments," she continues. "This support needs to be reflected through education initiatives."

Being mindful of the carers

Reducing the stress of caring

Lorn & Isles Rural General Hospital,
Oban

3

It is well recognised that carers face many stresses and challenges in their caring role. For some, the pressures exert a heavy toll on their physical and mental health, dignity and individuality. Carers report that their stress is compounded not only by the insufficient care shown to them by others, but also from lack of care and kindness they show to themselves.

A project team in NHS Highland has been working with partners to develop an approach to supporting carers of people with dementia to better address their own needs. The approach is based on the concept of "mindfulness", as community mental health nurse and project lead Gillian Davies explains.

"Mindfulness is both a skill and a way of living," she says. "It's about the here and now rather than being caught in the past or worrying all the time about the future, helping people to be more aware of how they think and behave to improve their lives. Mindfulness-based training is therefore focused on bringing our awareness to the

Mind Full, or Mindful?

present moment and experiencing this without judgement and by showing kindness to ourselves."

The project aim was to use a mindfulness-based cognitive therapy programme to enable carers to employ mechanisms to reduce the stress created by their caring role and improve their health, well-being, self-respect and dignity. The six-month programme was delivered to eight carers in Argyll and Bute Community Health Partnership who were recruited from the caseload of the Community Dementia Team.

"We interviewed the participants before the programme to explore their perceptions of how caring was affecting their health and well-being," Gillian says. "We found a sense of loss among the participants – loss of the person they were caring for as he or she once was, loss of relationship and loss of contact with previous activities. Time was seen as very precious and very pressured – people spoke of the difficulties in taking part in favoured activities without feeling they were 'snatching time' and of feeling guilty when they did so. And they felt their own dignity and self-esteem wasn't considered strongly enough by services.

"We were surprised at the carers' openness and honesty, and were hugely encouraged to realise how enthusiastic they were about undertaking the mindfulness programme – they felt this was something for them."

The original idea for the mindfulness programme came from Ylva Champion, a specialist community occupational therapist in the dementia team. Ylva ran the six-month programme, supported by Gillian and Andy Crabb, Dementia Advisor for Alzheimer Scotland. Essential support was also provided by the NHS Highland Research and Development Team in Inverness, Wendy O'Ryan, Senior Clinical Governance Facilitator for NHS Highland, and Dr Diane Fotheringham, Head of the Department of Nursing and Midwifery at the University of Cumbria.

Week by week, the carers' group came together to form a new sense of community. "Initially it was difficult for them to be at peace with themselves in a mindful place," Gillian recalls. "But as time went on, we could see them visibly relaxing, participating and engaging with mindfulness. By the end of the project, they recognised how important they were and understood that if they weren't caring for themselves, how could they care for somebody else?

"There was less frustration and less referring back to what life was like before dementia – they appeared to be in a much better place. And while they realised there was no more actual time in the day, the way they saw and approached their caring role had changed.

"There was a lot of emotion in the room and difficulties were aired," Gillian continues. "But mindfulness is about being in the present and being kind to yourself, so the group effect – with everyone gelling well and supporting themselves and each other – was in itself very helpful for participants."

Follow-up interviews on completion of the programme showed that carers recognised that applying mindfulness practices to their daily routine was bringing benefits not only to their health and well-being, but also to their caring role. "Applying mindfulness to daily life and routines enabled participants to value themselves and their role and, what is more, extend kindness towards themselves and the person they were caring for," says Gillian.

The emotions raised for the group facilitators and the potential conflicts that can arise when the locus of responsibility applies not only to the person in the room (the carer) but also to the person being cared for meant that being mindful and supportive of themselves was an important feature.

"As facilitators, we gained a huge amount from the sessions," notes Gillian. "But we had to look after ourselves. We need to be kind to ourselves to be kind to others. We were very fortunate to have support and supervision from Dr Alistair Wilson, a consultant psychiatrist who is a trainer with Mindfulness Scotland, and Dr Ishbel Dumughn, our clinical psychologist."

The plan now is to embed the findings from the project into practice more generally. Results will be disseminated through publications and local outlets and a new group will be established with members of the Community Dementia Team. Strategically, carers' health and well-being will be promoted through the Board's carers' strategy.

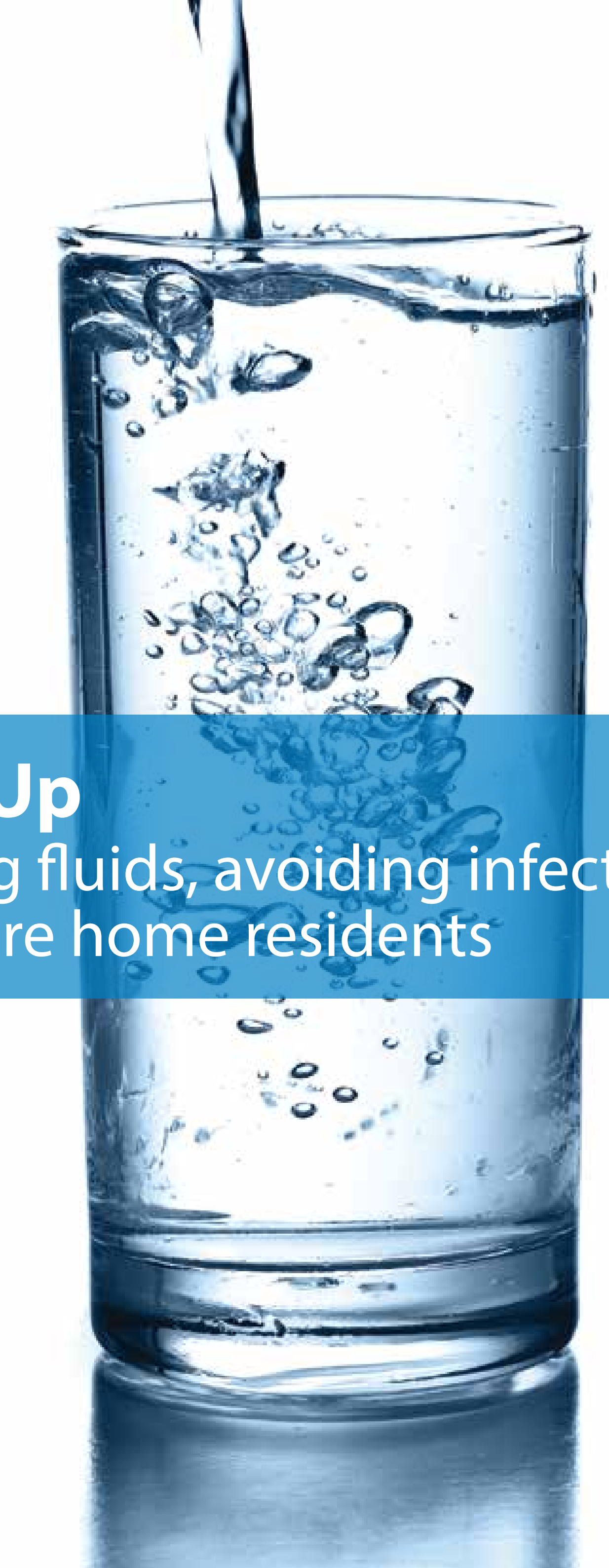
"It has been a long journey, but we feel we have made very positive steps," Gillian says. "There were challenges with everything from gaining ethical approval, to ensuring ongoing communication with partners across a wide geographic area, through to organising rooms where we could meet with carers. But we feel that having done the hard yards, we can now celebrate success."

Research like this is challenging, but the experience has not scared Gillian off. On the contrary, she is keen to do more, potentially to doctorate level, and wants to encourage fellow nurses to pursue a similar path.

> *"We were surprised at the carers' openness and honesty, and were hugely encouraged to realise how enthusiastic they were about undertaking the mindfulness programme – they felt this was something for them*

"We need to ensure that what we are doing with patients and carers is sound and will be beneficial to them," she says. "If we don't investigate what we do through projects like this, how can we change practice and move things forward?

"I'd say to my nursing colleagues – don't be scared by research. Trust your instincts, form a good team about you, reach out to good partners, and get involved. It's about better care at the end of the day, and that's what we all want."



DRINK-Up

Promoting fluids, avoiding infections among care home residents

Hill View Care Home,
Clydebank

4

Urinary tract infections, or UTIs, are the most common and serious infections among older people in care homes. They not only create discomfort and the threat of further health problems, but also erode people's dignity, as Professor Jo Booth of Glasgow Caledonian University explains.

"Having a UTI is a very undignified experience for many people," she says. "It's not just the pain and discomfort, problematic though they are, but also the use of products that many older people find repellent and undignified and changes to normal daily routines that bring distress and embarrassment. The seriousness of other conditions associated with UTIs, including falls and delirium, means they are not minor events – indeed, UTIs can lead to hospital admission and even death."

A risk factor for UTIs that is often overlooked is low fluid intake. This can result in concentrated urine and infrequent voiding, both of which are believed to encourage the growth of bacteria in the bladder. Directly addressing this common risk factor by increasing fluid intake as a method of preventing recurrent UTIs in care home residents is a potentially simple and dignified intervention, but has not previously been investigated. The 'DRINK-Up' (standing for 'Drink to Reduce INfection risK) feasibility study was therefore devised.

"Low fluid intake can make the bladder more susceptible to infection," Jo explains. "If we could increase people's fluid intake – even by just a little bit – it might help to make their urine more dilute and enable a flushing mechanism, preventing the occurrence of UTI and all the discomfort, distress and dangers they bring. So it's really about enhancing the person's natural ability to stave off infection."

Twenty-four elderly residents of Hillview Care Home in Clydebank who were known to have UTIs in the previous six months agreed to take part. An individually targeted daily fluid intake goal was set for each resident, with a minimum amount defined. This was supported by resident and family education on hydration and fluid intake, including how to use the Hydrant™ fluid delivery system, and support for staff to enable them to promote positive fluid management by offering and encouraging small amounts of individually chosen fluids frequently.

Rosaleen McKeating, a band 5 community nurse, was seconded to the project from the SPHERE bladder and bowel rehabilitation service in NHS Greater Glasgow & Clyde, with fellow community district nurse Joyce Phillips being seconded to SPHERE to cover for Rosaleen's absence. Rosaleen was central to overseeing the day-to-day running of the project in the home.

"Staff involvement was crucial," she says. "The assessment measures we used relied on staff encouraging, supporting and helping residents to increase their fluid intakes and recording the data accurately. I worked closely with them to deliver the intervention and identify the factors – positive and negative – that influenced its implementation."

The team assembled to deliver the project found a number of things that will be helpful going forward, but were not able to achieve a consistent increase in fluid intake for all residents.

"There may be a number of reasons for that," Jo explains. "Two thirds of the residents had a diagnosis of dementia, for instance, and eight had other significant medical problems like heart disease, stroke and cancer. Factors such as these can make it very difficult for someone to consistently drink more. If a resident started from a baseline of a low fluid intake, that was likely to persist, although we did manage to increase the intake of half the residents on the project."

Despite this, the numbers of UTIs in the group reduced from 51 in the previous six months to 37 during the six months of the project. The number of residents having a UTI fell from 20 to eight over the same time periods. "That was very encouraging," Jo comments.

Even more encouraging was the information revealed about falls, which can be linked to UTIs. Falls reduced from 52 pre-project to 28. "This was a significant decrease despite the small sample," Jo says. "Importantly, the number of residents who fell reduced from 18 to five."

> *Drinks are being offered more frequently, with greater consideration of the factors that might affect the person's ability and capacity to drink*

Focus groups held with staff at the end of the project indicated that their increased awareness of the importance of drinking had encouraged them not only to support the residents in the project to drink more, but also to promote higher fluid intake among all the residents.

"The staff spoke openly in the groups about how all the residents were being encouraged to drink more, even though there were differences of view on how much fluid frail older people required," Jo says. "This increased awareness of fluid intake, we believe, had an impact on the number of UTIs. Staff also endorsed ways of overcoming barriers to helping residents drink, including regularly asking residents if they would like a drink and offering drinks earlier and later in the day to extend the amount of time in which residents could drink – what we call 'the drinking day'."

Overall, this very simple project has been successful in raising awareness of the importance of fluids to the general health and well-being of older people and is now having a direct impact on practice.

"Drinks are being offered more frequently, with greater consideration of the factors that might affect the person's ability and capacity to drink," Jo says. "Routine practices in the care home that have an influence on fluid intake, such as processes surrounding morning care and mealtimes, are also changing."

Project group members have been enabled to develop new knowledge and enhance their repertoire of skills. Rosaleen McKeating, for example, believes she gained much from her involvement. "Being part of the project developed my knowledge and understanding of research processes in practice and increased my awareness of the importance of accurate data collection," she says. "It has pushed me to move out of my comfort zone to acquire new skills and knowledge that I will hopefully be able to use positively in my role."

DRINK-Up is the first study to formally test the relationships between increasing daily fluid intake and the number of UTIs and falls among older residents of a care home. Its results, according to Jo Booth, are promising.

"The potential benefits include the promotion of people's dignity and increases in their capacity for self-management," she says. "This highlights the ongoing need to develop and test methods to enable frail older people to drink independently."

Using all the senses

Enhancing mealtime experiences for older people with dementia

Haig House,
Erskine Home
Bishopton

5

We all know that food is essential for physical well-being, and most of us take for granted that we are more or less free to choose what we eat, where, when, and with whom.

For people with dementia in care environments, some of these essential elements of choice can be lost. Often, it is other people who make the decisions. In a culture in which choice of food and drink contributes to a sense of self, having no choice threatens dignity and personhood.

The challenge this presents has been taken on by staff of Haig House, a 30-bedded dementia unit in Erskine Home Bishopton. A team comprising nursing, speech and language, catering and academic staff worked with six residents and their families to adopt a "sensory" approach to mealtimes, as speech and language therapist Karen Herron explains.

"We wanted to try and enhance the dining experience of people with advanced dementia using an approach that encompasses all the senses," Karen says. "It wasn't just the content of the menu we were looking at, but the way the whole dining experience affected people – the sounds, sights, touch and smells associated with mealtimes, not just the tastes. We wanted to find innovative ways of supporting residents' choice of food, and not have care staff or families making decisions for them."

Working with staff from the unit and Margaret Brown and colleagues from the University of the West of Scotland, Karen helped to develop an intensive sensory education package based on learning from the university's pre-registration nursing programme. The package, which includes sensory impairment aids to encourage a deeper understanding of the experience of severe dementia when people are being assisted to eat and drink, was delivered to staff and family members before the 12-week intervention began, with staff focusing on particular senses in two-week spells.

"We realised that the project would need support from staff, so I discussed it with them, emphasising how it would empower them to have a say in what went on in the unit," explains House Manager and project leader Valerie Logan. "The active involvement of domestic and catering staff was also crucial to success. Catering manager John Booth, who was part of the project team, supplied small spicy 'tasters' and sorbets for between courses, with staff encouraging just one taste at a time."

The sensory approach focuses on trying to create a calm environment at mealtimes and stimulating all the diners' senses to enhance their experiences. "We made sure there was no TV or radio interruptions, and domestic chores like vacuum cleaning and clinical tasks such as dispensing medicines were not allowed during mealtimes," Karen Herron says. "We taught the staff to limit their verbal prompts with the residents to simple words like 'swallow', rather than using long descriptors, and to use gentle persuasion to engage people – 'is that nice?', 'are you enjoying this?', 'would you prefer orange juice or apple juice?'"

Promoting resident independence in feeding was a key concern, with the university providing some invaluable support. "Margaret Brown taught us the 'hand-over-hand' approach, a wonderful technique that empowers residents to be much more active in feeding themselves," Karen explains. And environmental issues were also taken into account. "Apart from eliminating background noise and disturbance as much as possible, we wanted to make the dining areas attractive," Karen says. "This meant supplying, among other things, bright and colourful tablecloths. Some staff had reservations about this, as they feared the residents might pull them off the tables, but we were able to argue that they would make the experience so much more attractive for them."

In addition to the aromas arising from the served food, the project team used an 'Ode' machine, a product that releases authentic food fragrances into living spaces before mealtimes, to stimulate appetites. The results of this were disappointing, however, as the aromas did not permeate sufficiently throughout the dining room. "A coffee percolator or bread-making machine might have more effect," Karen reflects.

Pre- and post-intervention assessments performed by the university showed that not only had communication at mealtimes among residents, families and staff improved, but also that the six residents had maintained weight over the 12 weeks, despite being close to the end stage of dementia. Their feeding difficulties decreased due to prompting from staff and the introduction of aids such as soft-tipped spoons to stimulate eating – a simple utensil that produced very beneficial results.

Valerie also noted some big benefits for the care team. "The project raised their awareness that they are empowered to make changes," she says. "The care assistants could see they were being listened to and that when they came up with ideas, things happened." Their ideas included having higher and squarer tables to enable access by wheelchairs and introducing dividers to make the area seem even more like a dining room. "We are getting these things now," Valerie says, "and we will soon appoint a dining room 'champion' to further promote staff engagement."

> *The sensory approach focuses on trying to create a calm environment at mealtimes and stimulating all the diners' senses to enhance their experiences*

Valerie and the team are determined to ensure the momentum and collaborative ethos the project has generated will be maintained.

"The project adopted a partnership approach involving a wide range of clinical, support and academic staff to enhance the dignity of people with advanced dementia," she says. "We have been able to empower residents, relatives and staff, just as we in the project team have been empowered by Margaret Brown's inspirational leadership and facilitation.

"The methods we chose to facilitate residents' food and drink choices were innovative, but simple," she continues. "Finding such ways to promote choice was ambitious and the process has really only just begun, as staff are continuing to develop their knowledge and understanding. Innovations in the project, such as introducing the soft-tip spoons, were small, but they made a difference and this has opened up new possibilities for the future."

Telling their story

Exploring Dignity Therapy for people with dementia

NHS Tayside

6

People have been providing accounts of their lives in oral or written form for thousands of years. The practice of passing on knowledge, experience and messages to subsequent generations has been valued and cherished throughout human history.

Dignity Therapy recognises and honours this fundamental process of communication. It offers a supported opportunity for people who are coming to the end of their lives to record their life story, which is then edited into a written document for them and their loved ones to keep – a lasting written legacy.

Recognising its potential with people who are in the early stages of dementia, researchers from the University of Nottingham, led by Professor Bridget Johnston, worked with colleagues from NHS Tayside and NHS Grampian to design a project to assess the feasibility, acceptability and potential effectiveness of a modified form of Dignity Therapy in improving their quality of life and reducing psychological and spiritual distress.

"People need to tell their story," explains Rev. Gillian Munro, Head of the Department of Spiritual Care in NHS Tayside, who was instrumental in working with Professor Johnston and the team to set up the project. "There is great healing power in story-telling. People can say what is important and special to them, what makes them feel proud or valued."

The project was based on the idea that Dignity Therapy can reinforce dignity and quality of life for people with dementia while they are still fully able to participate in the process. It aimed to help them capture a sense of who they are and who they have been by producing a document that will not only be relevant to their families after they have gone, but is also relevant now.

Common themes were seen across the documents that emerged from the interviews with people with dementia and their families, as Bridget explains.

"All of the documents were highly individual, but we could see that issues such as life reflection were figuring large," she says. "People were looking back and taking the opportunity to select certain events from life. Most of the people I saw were in their late seventies or early eighties, and they could track right back into early childhood.

"One lady I interviewed had very, very distinct memories of her first day at school – she could remember the green paint and how calming it was. 'Green is still my favourite colour', she told me, and she was wearing green when we met."

People recognised and talked about the personal legacy aspect of Dignity Therapy, which offered them an opportunity to consider and record what they would want to say to their families. Bridget recounts how one man told her: "I would like to be remembered as a loving, helpful father. You get back what you give; you get less selfish as you get older". Another said: "I've certainly enjoyed becoming a grandfather, and I think it's great to have time to get to know the grandchildren."

Although there was some avoidance of thinking about or discussing the future and what lay ahead, the Dignity Therapy document provided a sensitive way of allowing legacy and history to be preserved, without causing unnecessary distress or unwanted discussions. As one participant put it: "It's memory stimulation – it's the only way to face it at the moment, unless they come up with a drug to bring your memory back."

Part of the Dignity Therapy process involves the therapist going back to the participant after the editing has been completed and reading the document aloud to them. "It's a very moving thing to actually feed someone's words back to them," Bridget says. "Sometimes the person would question if what I was reading to them was right, or be astonished about how I knew so much about them. One person said: 'When you hear someone else saying it, it hits you in the back of the throat a wee bit. But it's all part of the story.'"

User/patient involvement was a very important principle in the study. Collaborators such as Emma Law, who manages the Scottish Dementia Research Network, enabled the project to engage with network advisers who are affected by dementia. Through contacts such as these, 28 participants were enrolled, with seven people who had been diagnosed as having early-stage dementia and members of their families being interviewed by trained Dignity Therapy interviewers Professor Bridget Johnston and Professor Sally Lawton. Other key people such as care home managers were also interviewed and a focus group was held with people with dementia to see if Dignity Therapy was something they thought was worth taking forward.

The project also unearthed some potentially problematic issues that would need to be thought through before further Dignity Therapy work with people with dementia could be taken forward.

"There are potential issues with life reflection in any form," Bridget explains. "For instance, you can find someone speaking about the significance of a previous spouse with their current spouse sitting alongside. These are some of the issues we need to think about and explore before Dignity Therapy for people with dementia could be adopted into clinical practice."

But Bridget believes the project has provided good evidence that Dignity Therapy is both feasible and potentially beneficial for people with early-stage dementia. The knowledge and insights gained from it will form the basis of further research proposals and funding applications, with consideration also being given to including people with more developed disease progression.

"Participants used the Dignity Therapy as an opportunity to reflect on their life, their successes and regrets," Bridget says. "They considered the people, achievements and things they valued and appreciated and displayed a good ability to recollect minute details from the past. They divulged information about likes, dislikes and the origins of habit that might be helpful in explaining future reactions and behaviours. Information like this might not have been divulged through other means.

"And the people who participated really enjoyed it," she concludes. "Giving something of themselves to their families was really important to them."

> *There is great healing power in story-telling. People can say what is important and special to them, what makes them feel proud or valued*

As Gillian Munro reflects, the Dignity Therapy approach offers a possible way for people with dementia to lay down a marker in what can be rapidly shifting sands.

"People living with dementia can feel their story slipping away from them," she says. "In bringing nursing and spiritual well-being together, we hope Dignity Therapy will reassure them that they can be remembered the way they want – this will be their story."

Project details and grant awards

Project	Leads/contacts	Institution	Grant	Setting
Enhancing dignity through relational caring conversations	• **Professor Belinda Dewar** belinda.dewar@uws.ac.uk • **Tamsin MacBride**, University of the West of Scotland • **Staff, residents and families** from Carnbroe Care Centre	University of the West of Scotland	**£9602**	Carnbroe Care Centre, Coatbridge
Raising awareness of sensory impairment with nurses working in the community	• **Dr Annetta Smith**, University of Stirling annetta.smith@stir.ac.uk • **Karen Macleod**, Community Staff Nurse, NHS Western Isles	University of Stirling	**£8634**	Western Isles Sensory Centre & Community
Being mindful of the carers	• **Gillian Davies**, Practice Education Facilitator/ Community Mental Health Nurse gilliandavies@nhs.net • **Wendy O'Rya**n, Senior Clinical Governance Facilitator, NHS Highland wendy.o'ryan@nhs.net	NHS Highland	**£7500**	Lorn & Isles Rural General Hospital, Oban
Drink to Reduce INfection risK-Up: a dignified approach to preventing urinary tract infection in older people resident in care homes	• **Professor Jo Booth**, Glasgow Caledonian University Jo.booth@gcu.ac.uk • **Dr Rona Agnew**, NHS Greater Glasgow & Clyde	Glasgow Caledonian University	**£9770**	Hill View Care Home, Clydebank
Food for thought: enhancing dietary preferences for the person with advanced dementia	• **Val Logan**, Haig House Manager valerie.logan@erskine.org.uk • **Margaret Brown**, University of the West of Scotland margaret.brown@uws.ac.uk	Erskine	**£9925**	Haig House, Erskine Home Bishopton
Living well with dementia	• **Professor Bridget Johnston**, University of Nottingham bridget.johnston@nottingham.ac.uk • **Professor Sally Lawton**, NHS Grampian • **Emma Law**, NHS Tayside • **Gillian Munro**, NHS Tayside • **Dr Cesar Rodriguez**, NHS Tayside	NHS Tayside	**£8000**	NHS Tayside
		Total	**£53 431**	

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