Dignity in Dementia:
Transforming general hospital care

Results from an online survey consultation of carer and patients
Final report prepared for the RCN, July 2011

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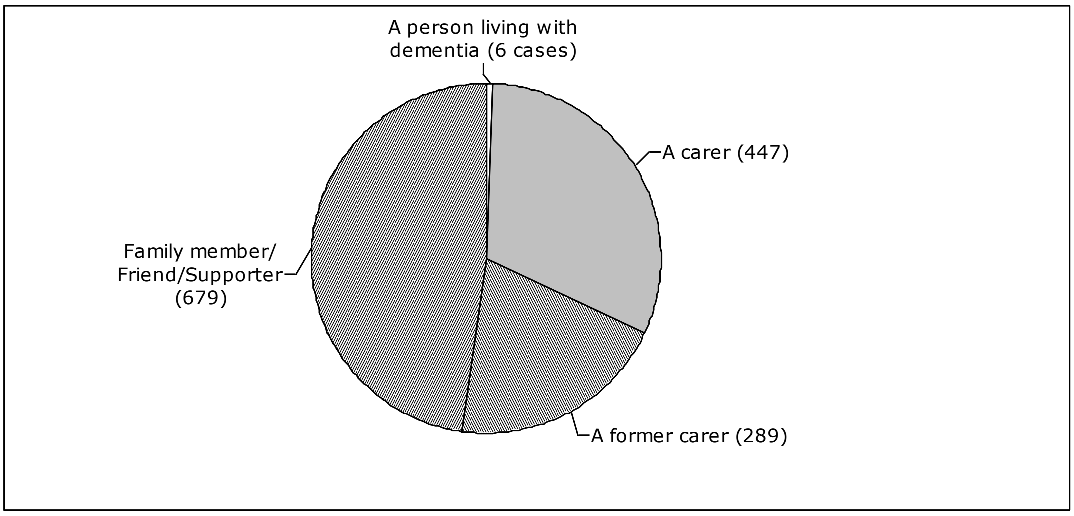
1. Introduction and respondent profile

Following on from a survey of professionals in January 2011 the Royal College of Nursing (RCN) commissioned Employment Research to design an online survey tool to collate responses from dementia patients and carers people with dementia. The survey was launched on 6th May 2011 and by 30th June 1484 responses had been received. This is a far larger response than was anticipated and lends significant weight to the findings.

This brief document summarises the main findings from the survey. This includes both closed question quantitative analysis and analysis of open response questions that have been coded using a coding frame agreed with the RCN.

Across all respondents just six were people living with dementia, a third (32%) are current carers of people with dementia, one in five (20%) were former carers and nearly a half (48%) were friends, relatives or supporters of people with dementia. In the following analysis

Figure 1: Respondent role and link to dementia (percentages)



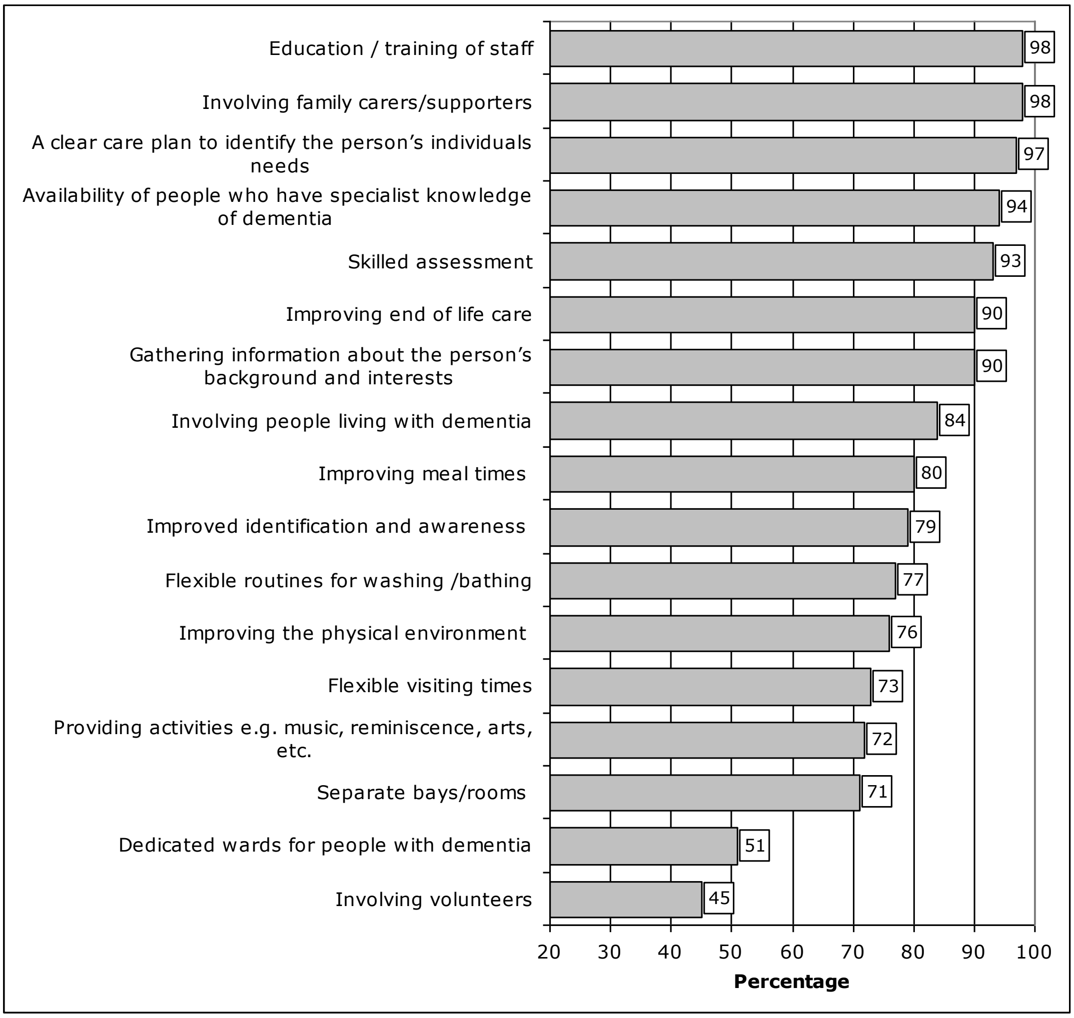
Source: Employment Research/RCN Dignity in Dementia Carers Survey, 2011

Most respondents experience of dementia comes from in patient admissions (69% of all responses), 2% were from day admissions, 9% from visits to A&E/emergency department, and 5% from outpatient appointments. In addition 15% indicated ‘other’ experience which, more often than not, was a combination of the above. A half (55%) of respondents were reporting on behalf of someone living in their own home, 28% about someone in a care home, 9% said this was not applicable and 3% said the person lived in another persons home at the time of admission to hospital.

2. Important features of quality dementia care

A number of approaches have been identified by carers as being important in delivering better care for people with dementia and their families, while in general hospital. Figure 2 shows the percentage of respondents who indicated each approach as being 'very' important. Seven approaches were mentioned by more than nine in ten of all respondents, and almost all were indicated as being 'very important' by three quarters or more of all respondents. The figure has ordered the approaches in ascending order from most cited to least cited.

Figure 2: Importance of different factors in improving the experience of being in hospital for people with dementia (percentages indicating the factor is 'very' important)



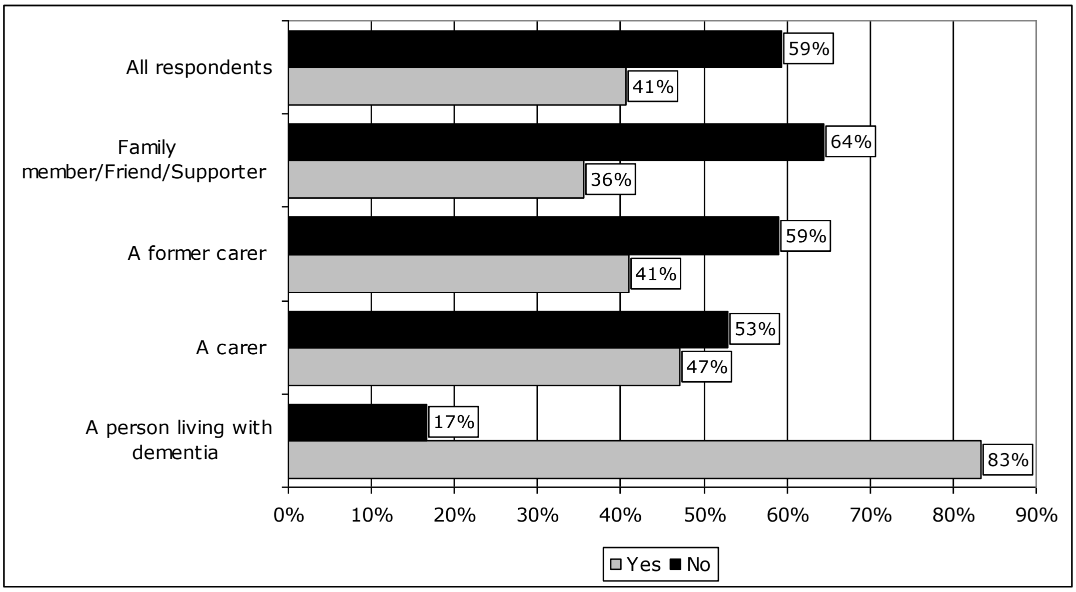
Source: Employment Research/RCN Dignity in Dementia Carers Survey, 2011

With so many respondents seeing each feature as being 'very important' to the quality of dementia care, there were no discernible differences in the views between carers, former carers and family/friends of people living with dementia.

'This is me' is one example of a tool for gathering personal information. The survey asked respondents if they were familiar with it. Forty one per cent said they were familiar with the document and of these just under a half (48%) said they had used it.

There is some difference between the type of carer in whether or not they reported being familiar with the document as Figure 3 demonstrates. Just under half (47%) of current carers reported being familiar with it compared to 41% of former carers and 36% of family/friends. Of the six people living with dementia five said they were familiar with the document. However, there was no variation in whether or not they had used the document between types of respondent.

Figure 3: Are you familiar with *'This is me'* (an example of gathering information for use in hospital settings) percentages yes/no



Source: Employment Research/RCN Dignity in Dementia Carers Survey, 2011

Respondents had come across a variety of other formats/documents/plans during their experience of dementia care. The coding for this question was split into two sections. First, 397 respondents indicated the source of other documents/formats etc. This included one in four (27%) who referred to information gathered by other agencies, for example, GPs, care homes, leaflets (not specified), handbooks and letters etc. and 149 respondents named particular formats. These included:

Table 1: Other formats specified by respondents (cases)

Type of document	References
Scrapbook/Memory box/book	15
Posters/collages/photo-board	6
Developed our/my own/developed by family/carer	23
Learning Disabilities/Difficulties System – general (not Life Story)	12
Passport Scheme e.g. learning disabilities/Mencap passport	25
Traffic Light (not Life Story)	7
My Favourites (published by Vanity First)	1
Generic Life Story tool/life histories	29
Generic All About Me/Remember Me/Who I am	37

Source: Employment Research/RCN Dignity in Dementia Carers Survey, 2011

Respondents to the survey were also asked if they could think of any other approaches they felt were important to improving the experience of dementia care in hospitals. All responses were coded and the table below shows the summary data. A repeated message that comes through a variety of responses to the questions in the survey is the need for more understanding of dementia, improved respect and dignity of for dementia patients and better communication with all concerned, patients and their families. Also mentioned is the need for increases in the time allocated to dementia care, improved continuity and better assessment.

Table 2: Other approaches seen as important to improving care in general hospitals

Example of other approach mentioned	Responses (% of cases)
Training for all staff/improve understanding of needs of dementia patient	306 (31%)
Respect/dignity/better attitude of staff – no shouting at patients/better communication skills/patient involvement	213 (22%)
Communicating with carers/family – listening/opportunity to discuss progress privately/kept in loop regarding care	210 (21%)
Sufficient time – for listening/dealing in clear, concise way with dementia patients	134 (14%)
Continuity of care on the ward/on a daily/weekly basis/reduce stress/named nurses/1:1	107 (11%)
Sufficient staff to deal with dementia patients	101 (10%)
Better assessment/adapt assessment forms i.e. passport/traffic light system/pain and medication assessments/less waiting	79 (8%)
Widespread use of “This is Me”/Life histories/nurses to take note of personal information provided/familiar items around	76 (8%)
Great access for carers – i.e. staying over/visiting at any time/helping patients at meal times	71 (7%)
Specialist nurses/Nurse champions	68 (7%)
Separate dementia wards – less moving between wards/units	56 (6%)
Keeping to routines/diary/daily planner/detailed medication notes/care plan/info shared by all staff	41 (4%)
Safe and secure environment for patients/quiet/educate “other” patients	38 (4%)
Stimulation/activities	38 (4%)
Continuity of care between agencies/departments i.e. fracture clinics/A&E/eye etc/better sharing of information	37 (4%)
Food intake/monitor red trays/ensure meals are eaten/ability to feed/protected meal times	29 (3%)
Greater levels of supervision to ensure patient safe/not left on own too long	26 (3%)
Volunteers	16 (2%)
Equipment and signage	15 (2%)
Not isolating patients – i.e. in a side room	13 (1%)
Butterfly scheme – labelling patients/”stigmatising” patient – lack of confidentiality	13 (1%)
End of life/palliative care issues	12 (1%)
Fluids/attention to fluid intake	10 (1%)
Liaison with local groups – i.e. Alzheimer’s Society/Dementia Steering groups/religious groups	10 (1%)
Other comment made/not relevant	5 (<1%)
Number of responses	***1724***

Source: Employment Research/RCN Dignity in Dementia Carers Survey, 2011

Some specific examples of respondent suggestions as to the type sof approaches they would like to see adopted are given below:

> *Perhaps it would be better to take out the word 'experience'* [referring to the question] - *what is needed is improved care. An 'experience' seems to imply a choice! Nursing staff who know the patients on their wards as individuals - there is no excuse for not knowing who is on the ward. Dedicated nurses trained in care of the dementia cases just has you have children's nurses. Everyone is not suited to care for the dementia sufferer.*
>
> *I think that a specialist nurse or trained in care of dementia patients would be a great help to general nursing staff as point of contact for nurses and would also be provide family members with in depth information on the type of dementia affecting their relative and what they can do to help them. In the hospital where I work there is no such specialist nurse available other than the head injury nurse who does not deal with long-standing dementia other than that caused by Head injuries.*
>
> *It would be helpful to educate general nurses and nursing auxiliaries on how to manage people with dementia who present as challenging. I feel it would be beneficial to have a mental health nurse on geriatric wards who can provide the specialist care that people with dementia require whilst in the acute hospital setting.*
>
> *Appropriate trained staff who not only understand the concept of different levels of dementia and how to manage patients accordingly, but have a passion for caring for patients with dementia. Secondly this particular group of patients need staff to have the TIME to care for them.*
>
> *I feel specialist staff must be provided with correct training to be able to competently care for patients with dementia. Without this it is hard when patients are placed on wards were staff don't have the correct knowledge or time to be able to give their full attention to the patient, which I feel is essential to maintain dignity and the standard of care that patients need. I feel passionate about this subject and as a Student Nurse, this is the type of area I would love to work if there were jobs available.*
>
> *I do believe that staff within general hospitals have limited understanding, training and time to spend providing quality care for people with dementia. this is not a criticism, but merely and objective observation from both working and personal experience. I also feel the mindset of hospitals (task orientated), does not allow for staff to think "outside the box" when caring for people with more complex needs, and I really don't see this changing under current pressures to provide care. I do believe specialist wards for people with dementia who require hospitalisation would be the best way forward.*

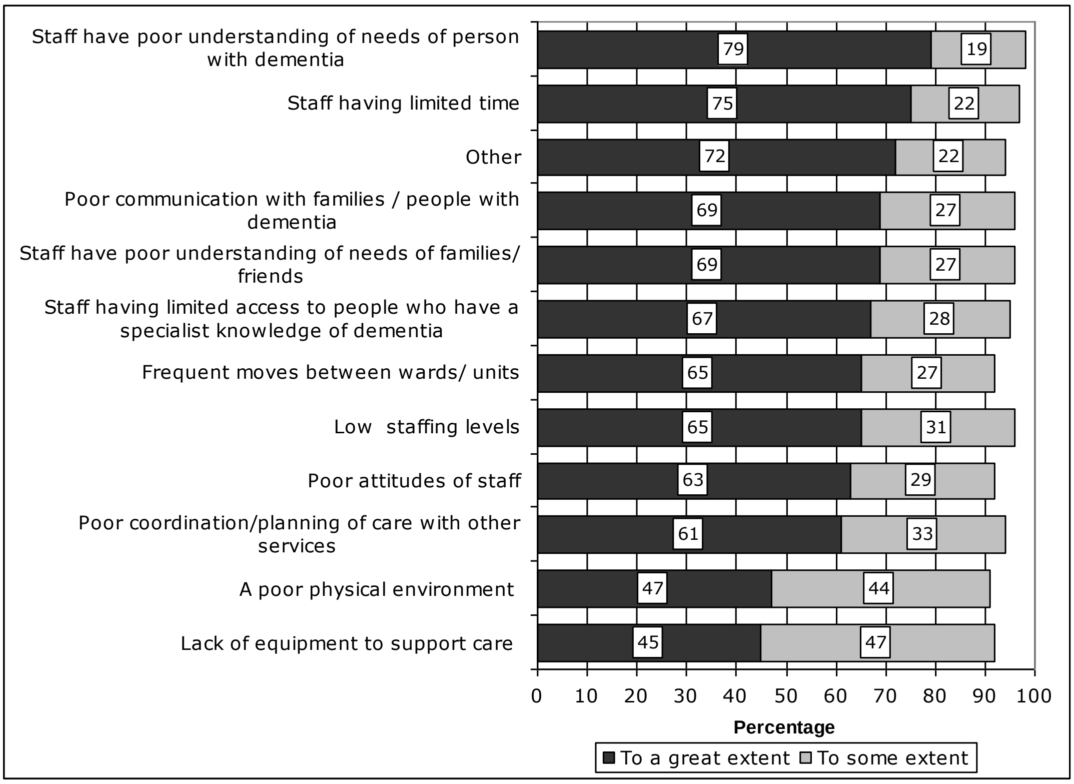
3. Barriers to effective dementia care

Respondents were also asked to indicate the degree to which different factors acted as barriers to the provision of good quality dementia care in hospital. Figure 3 below shows which barriers mentioned by respondents were cited most frequently. Staff understanding and time were the two most frequently mentioned barriers, followed by 'other' factors. Around two thirds of respondents indicated that a range of other factors were also barriers to the provision of good quality care to a great extent. This included:

- Staff having a poor understanding of the needs of families/friends
- Poor communication with families/people with dementia
- Staff having limited access to people who have a specialist knowledge of dementia
- Low staffing levels
- Frequent moves between wards/ units
- Poor attitudes of staff
- Poor coordination/planning of care with other services

Mentioned less frequently as a barrier to a great extent, but still by around a half of all respondents were the physical environment and a lack of equipment to support care.

Figure 4: Barriers to the provision of good quality care in hospital (percentages indicating 'to a great extent' and 'to some extent')



Source: Employment Research/RCN Dignity in Dementia Carers Survey, 2011

‘Other’ barriers were mentioned by most respondents, or they wanted to give further explanation as to the nature of the barriers they had highlighted in the closed response section previously. The main responses and some examples of the comments provided include:

Staff have poor understanding of needs of dementia patients/lack of supervision ensuring patient safe/not left alone too long (mentioned by 22% of cases)

Not taking time to understand a person with dementia, because of lack training and staff shortages.

Lack of understanding from other disciplines, i.e. radiographers and imaging, ward clerks, domiciliary staff and so on. Teaching all NHS hospital staff about dementia during their work induction must become compulsory across the country.

Poor meaning and understanding of dementia is of key concern, to ensure dementia care is improved, awareness training is essential. Dementia care is now a national priority and literature attempts to explain why, the key issues are that nurses find the experience challenging, yet, nurse training (Nursing Degree)fails to include adequate mental health training input.

1. lack of knowledge around dementia. 2. lack of genuine interest in caring for the patient as a whole-happy to treat the pneumonia but not the rest of the person! 3. lack of treating patient and families with dignity-one size fits all 4. lack of appreciating advice of other MDT staff such as CPN and carers which may include carers 5. lack of interest in caring for patients with dementia

Poor communication with families/dementia patients/restricted visiting times (18% of cases)

Disregard of family input which is vital and lack of communication with families about their family member.

Having to argue that it would be better if one of the family could stay with my dad 24/7 - we have a rota system at home and he is used to one of us. Being made to leave him, unwell, in a strange noisy crowded ward with busy staff was terribly upsetting - when I arrived the next morning early, having to argue again that I wanted to see my dad outside of visiting hours, and then getting to his bedside to find him naked, on the floor, and wet, with bags of other peoples clothing and items all around him to show he had wandered all night gave me nightmares for months afterwards.

Staff do not listen to what family members have to say and quality of discharges are appalling-in my mother's experience over the last eight months she has been admitted to hospital five times and four of the five discharges in my opinion as a registered mental health nurse have been unsafe discharges.

Unsympathetic doctors and health professionals not listening to relatives who know them best. Carers being totally ignored and doctors asking patients questions they cannot answer e.g. where does it hurt?

Poor assessments/checking medication needs on transfer/care plans/delays in discharge/poor judgements made after poor assessment leading to unsafe discharge (14% of cases)

I've been present when some staff are carrying out patient assessments (doctors & nurses), which is good in theory, but in the process they ask questions in groups rather than one at a time. As a result the person with dementia can only remember the last question in the group or is too overwhelmed to answer. This doesn't give the person with dementia a chance to contribute to the assessment and turns it into a sham.

Targets for length of stay. Patients with dementia often take longer to get 'back on their feet' than those patients who are fully alert and orientated. Often patients who have spent a long time in hospital who are older are considered to be 'cognitively impaired' - if you had spent 4 months in the same hospital seeing the same staff, eating the same food with the same daily routine...would you be able to remember what you had for lunch the previous day?

Rush to discharge without proper assessment and liaison with social services and without proper package of care being arranged.

Not checking medication needs properly on transfer to hospital - anti-depressants were stopped for 10 days. Level of training and understanding of staff is not consistent.

Staff having insufficient time to listen/explain clearly and sensitively/don't answer questions adequately (12%)

Staff are very quick to say they don't have time, and this is true in some cases. But they do take time to do things to people with dementia that don't help. If they just used that time to do some of the things that will make a difference then they could make things better with no extra resource. An example would be repeating your name when you are communicating, getting pain relief to be regular rather than "as required" or prn, cutting down on the noise and increasing the light level. It is not about time, it is about nurses not even knowing the basics of what they could and should do because they don't get that at pre-registration level.

I was told that the nurses on the ward had'nt got time to 'baby sit' my mother, who had just been found wondering around the car park on a freezing cold day, pouring with rain, she was dressed in a hospital nightdress which was completely open at the back. The sister on the ward was adamant that she couldn't get out of the ward, and would not accept responsibility. When my father was in hospital there was an outbreak of novo virus. We weren't allowed to visit, he was in a side ward on his own for 3 weeks. The staff just would not listen, didn't seem to care that because of his dementia, it was important for his recovery that he should have contact with family at least.

In addition to these main themes the following issues were also mentioned.

Table 3: 'Other' barriers to effective dementia care (percentage of cases)

Respect/dignity – "talking to patients as if they are children". Don't shout/abuse	10%
Poor continuity of care on wards/nurses changing shifts/lack of info on case notes/shared information/lack of knowledge	10%
Poor attitudes of staff/lack of interest	9%
Lack of adequate training of staff	8%
Low staffing levels	8%
Poor coordination/planning of care with other services/care on return home	7%
Poor communication skills	4%
Ensuring enough food/fluid is taken/poor nutrition as patient can't feed themselves/more staff needed to help at mealtimes	3%
Lack of equipment to support care/financial restraints	3%
Lack of awareness when patients disorientated after move to new unit/scared and aggressive	3%
Poor basic care/incontinence/personal hygiene/helping with washing	3%
Language and cultural barriers/strong accents can be confusing for dementia patients	2%
Medicating "disruptive" patients when just scared/disorientated/inappropriate medication	2%
Staff have limited access to specialists	2%
Lack of understanding/knowledge of GPs/consultants	2%
Lack of activities/stimulation	1%
Lack of understanding/acceptance of the condition from families/carers/poor attitudes	1%
Other comment made/not relevant	1%
Age discrimination	1%
Frequent (unnecessary?) moves between wards/units	1%
Lack of support/supervision for nurses dealing with aggressive patients/nurses have to do things which can be distressing	1%

Source: Employment Research/RCN Dignity in Dementia Carers Survey, 2011

4. Other improvements to dementia care

Finally, at the end of the survey, respondents were asked to report on anything else they felt might lead to an improvement in the experience of care for people with dementia and their families and carers in general hospital. Many of the comments corroborated responses given elsewhere but were coded nevertheless. Table 4 below summarises the main themes that emerged from this coding process.

Table 3: 'Other' improvements to the experience of care for people with dementia (responses and percentage of cases)

Suggested improvement	Responses	% Cases
Better understanding of needs of carer/family. Better communication with carers/families. Sharing/listening/supporting/ keep them in the loop/educating families/carers	216	28%
Better understanding of needs of dementia patients/awareness of patients (treat the person not just the dementia)/interacting with dementia patient	177	23%
More time to spend with patients/listen/time to explain/clarify clearly/involve patients more/communication	108	14%
Training for all staff	107	14%
Continuity of care on daily/weekly basis/familiarity for patient/better case notes/pass on information/named nurses	64	8%
Safe environment/quiet areas/therapy rooms/orientation boards/better signage/alert system on people who wander	60	8%
Better basic care – i.e. help with washing/toileting (not left to "pee in the pad – that's what it's for")/feeding (not leaving "unopened packets which patients can't open")/medication left on bedside table/items out of reach	52	7%
Separate dementia wards/less moving between wards/units i.e. "moves between wards distressed my mother most"/single sex	49	6%
More respect/dignity towards patients/not shouting at or treating like a child	47	6%
Activities/socialisation. Better use of "This is Me"/Life histories provided by carers/family	47	6%
More staff/better skill mix	46	6%
Specialist staff/dementia champions	46	6%
Fast track through A&E/discharge etc to reduce lengthy stays/better liaison with care homes	45	6%
More access for carers i.e. visiting times/stay overnight	43	6%
Better attitude of staff/"don't care"/more compassion	39	5%
Better assessment on arrival in ward/thorough check on medication needs on transfer/better liaison with care homes	25	3%
Liaison with mental health teams/community help/local groups – i.e. Alzheimer's Society/ Dementia Steering groups	23	3%
Other comment made/not relevant	21	3%
Better supervision/management on ward/support for the nurses	18	2%
Govt funding/carer allowances/reference to NHS	13	2%
Use of volunteers/HCAs	11	1%
Written care plans	8	1%
Understanding and consideration from other patients/more consideration for other patients	4	1%
GPs to have greater understanding/take more responsibility	4	1%
Number of responses	***1276***	

Source: Employment Research/RCN Dignity in Dementia Carers Survey, 2011

Again, as reported on above, improved awareness and understanding both of the needs of dementia patients and their families/carers is the most frequently cited improvement that is thought to be required by carers. This would be well supported by allowing staff more time to spend with patients and improving the training that is provided to staff. Also, there is a reported need for safer environments and improved continuity of care so each patient's needs and are understood and appreciated. Below are a selection of the more detailed comments and suggestions that were provided by respondents.

> *In an ideal world there would be more nurses on the ward, then each and every patient would be able to have good quality care as you would have the time not only to be able to see to their hygiene needs and assist patients with feeding but have the time to sit and talk with them (wouldn't that be nice) while also being able to maintain the mountain of paper work you have a legal obligation to fulfil.*
>
> *It is not necessarily the numbers of staff in the clinical area that is most important but the skill mix. The number of registered nurses who are able to deal with complex communication needs, dietary care, challenging behaviour and physical impairments and who are experienced at care planning and assessment is of greater importance than just increasing staffing levels per se. These patients need intensive care and registered nurse staffing ratios such as those found in other critical care areas like ICU should be mirrored in areas where elderly patients with dementia are being cared for.*
>
> *Managers need to look at the staff to patient ratio within elderly care - there should be a legal/recommended ratio. Paediatric care has higher level of staff to patient ratio due to the vulnerability of the patients - this needs to be transferred to older peoples' nursing. In my hospital we have a Dementia Steering Group which meets every 3 months - members include consultants, matrons, practice educator, palliative care, speech and language therapist and patient panel.*
>
> *There needs to be a response team in big busy hospitals whereby a carer or nurse or even both can come down to a ward and devote an hour or two to be with a patient with dementia during the times when the ward is especially busy. This would prove useful in wards where the pace of the work is very fast and the staff are very busy such as Medical Assessment Units and also on Surgical wards were there might be a lack of insight into the condition and perhaps an inappropriate environment to cater for the clients needs. This would be actioned by a risk form that needs to meet a certain criterion and be counter-signed by a lead nurse.*
>
> *Each ward should have one or more dementia champions. The 'link' could do unannounced walkabouts to see what is happening. The hospital where our relative is at present has a comments box. Emptied monthly, so hardly responsive!*
>
> *I feel the most important aspect that needs improving in hospitals and care homes is the training staff need to be able to provide good quality care for people with dementia in particular. My grandma has Lewy Body dementia and from my experience the care needed to ensure a good quality of life needs to be thorough and consistent. It can be extremely time consuming and repetitive but it needs to be done well for results which won't only benefit the patient but will give the staff a degree of satisfaction in their job when they see that there hard work has helped. Level of staffing and staffing attitudes affect this considerably, especially in a hospital setting.*

I think the main problem has to be the lack of training and poor staffing levels. Its easier and cheaper to sedate someone than it is to provide one to one care for a patient who is acutely confused. Unfortunately the rigid routines of general wards just don't have the flexibility to allow for these patient's very specific needs and all too often they are simply seen as a nuisance.

Training & raising awareness is first step, once enlightened staff and teams make fantastic efforts to improve care with resources already have. Role of champions and link workers supports a structure but still staffing and time is needed to provide both adequate care and fulfil all CQC requirements to be fit staff and environment for purpose.

Staff need so much more training and they need to be told that dementia sufferers by diagnosis are discriminated against because they cannot voice their wishes therefore a great deal of skill is required to pre-empt the needs and wishes of dementia sufferers and their families. They need to be more aware that asking a dementia sufferer if they have a pain or feel ill may not get a true or realistic answer. The level of understanding in hospitals is pitifully low perhaps they are too busy, I don't know but sure as eggs is eggs the bottom of the heap is always dementia because THEY HAVE NO VOICE TO COMPLAIN WITH which makes them so vulnerable. Cameras in hospitals where dementia patients are would help protect them especially if they were together in small units with highly trained staff. at present they are free to walk out of the hospital which happened to my Dad. he just walked out and got on a bus when I asked why he had been allowed to do this I was accused of interfering and snapped at. I was told off because my Dad pulled out his line giving him a blood transfusion, I wasn't even in the hospital at the time. How could I be so stupid!? I think families need much more support and respect from all hospital staff. I did come across a few gems but they were very rare.

Flexible visiting times would enable family/carers to be with the individual with dementia at the most appropriate times for example mealtimes when the person may need more assistance. Most carers would willingly assist and be a partner in their loved ones care. we all know that the wards are run on a skeleton staffing level but usually carers will try to adapt to the needs of the service and particularly the individual. The individual would then benefit from a familiar face to assist them and to allay their fears of being in a quite alien setting. This could be extended to other periods when a familiar face would be useful for example to hold the persons hand during a procedure or when information is given.