

HOSPITAL CARE FOR PEOPLE WITH DEMENTIA CONVERSATIONS 2014

**PREPARED BY
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ALZHEIMER'S AUSTRALIA SA

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[1800 100 500](tel:1800100500)
(NDH is an Australian Government initiative)

INTRODUCTION

In November 2014 Alzheimer's Australia SA held forums across metropolitan Adelaide for people living with dementia, their carers, families and service providers, to discuss hospital care for people with dementia.

Participants shared their experiences of the hospital journey through pre-admission, the hospital stay, discharge and after care. They outlined what was needed to make future hospital journeys dementia friendly.

One hundred and five people attended the forums in northern, southern and central locations, with several additional people making comment.

In general, the conversations confirmed the findings of other reports, in particular those of the Australian Institute of Health and Welfare (2013) and Alzheimer's Australia (2014).

These South Australian voices highlight for the state government the personal costs and impact of the hospital journey, as the government responds to and implements the SA Health Services Plan for People with Dementia (and Delirium) 2014-2018 and develops the Delivering Transforming Health Proposals Paper February 2015 initiatives.

The Forum Opportunity

Drawing on the Lived Experience

People living with dementia, their families and carers are integral to informing the development of services that best meet their needs. Regular consumers forums provide a means for these people to share their experiences with others on particular topics.

Through these conversations, participants discuss what is happening to them and what could be done by the wider service sector and Alzheimer's Australia SA itself to support them.

The involvement of service providers in forums, such as those discussed in this report, adds a further dimension. This provides Alzheimer's Australia SA with the best picture possible in its representation of the lived experiences and needs of people with dementia.

Sharing, Learning, Challenging

Forum discussions are informal conversations based on open-ended questions within the core agenda. This results in a broad range of responses, extensive sharing of information and experiences and a large number of recommended actions.

Comment Sheets give the participants an opportunity to add to the round-table conversations.

People unable to attend are invited to make a comment or tell their story through telephone or email contact.

PARTICIPATION

	Person With Dementia	Carer*	Service Provider	Not stated	TOTAL
Northern Adelaide	3	21	10	1	35
Southern Adelaide	3	13	11	2	29
Central and Western Adelaide	10	21	10		41
Stories		3			3
TOTAL	16	58	31	3	108

- Including 5 carers/family members who work as service providers

PRESENTATION

Lesley Habel

HOSPITAL CARE FOR PEOPLE WITH DEMENTIA

HOSPITALISED PEOPLE WITH DEMENTIA: THE FACTS

Dementia care is core business for acute care hospitals.

People with cognitive impairment in acute care account for 30-50% of total patient admissions. (Christie & Cunningham, 2011; Draper et al, 2011; Travers et al, 2013).

Common reasons for a person with dementia requiring hospitalisation are chronic condition management, hip fractures and other injuries, lower respiratory tract infections, urinary tract infections and delirium.

However, we are far from providing a good care experience for many of our patients with dementia. Hospitalised people with dementia face the risk of many adverse events when hospitalised, including physical and cognitive functional decline, under-nutrition, skin tears and fall-related injuries (Draper et al, 2011). SA Health reported in 2012 that 33.8% (n=6027) of falls in 2011/12 were experienced by patients diagnosed with dementia.

Key issues within acute care when dealing with patients with dementia include:

- Nearly half of hospitalised people with dementia do not have 'dementia' recorded as a diagnosis.
- Referral to a diagnosis of dementia is inadequately documented in care notes. The Australian Institute of Health and Welfare (AIHW) states that 'dementia when present was documented in the notes in less than half the time'.
- Hospitalised people with dementia are at increased risk of developing a delirium. Rates of delirium in hospital are estimated as 10-31% at admission, 3-10% during hospital episode and 70% when in Intensive Care Units.

- Hospitalised people with dementia are almost twice as likely to die in hospital than those without dementia.
- Average length of stay in hospital is 16.4 days for a person with dementia, compared to 8.9 days for other patients.

(AIHW, 2013; Draper et al, 2011; Sampson et al, 2009)

WHAT ASSISTS IN IMPROVING QUALITY OF CARE OF A PERSON WITH DEMENTIA IN HOSPITAL?

There are many contributors that can improve the quality of care given to hospitalised people with dementia.

Widespread education for acute care staff on the condition of dementia and the special needs these patients have whilst in care assists greatly in improving care (McCloskey, 2004).

Health care professionals need to engage more with family carers to assist hospitalised people with dementia. They need to integrate carers into their loved ones' care when appropriate.

Psychosocial strategies such as memory cues (calendars, photos and clocks for example) are effective as is providing a calm environment that is well organised with good lighting.

Signage is also an important environmental consideration in addition to orientation signs around wards. However, the signage must be lowered to patients' eye level in order to gain their attention and make an impact (Hanley, 2004; Cunningham, 2006; Goodall, 2006).

Other strategies to improve the quality of care given in hospital to people with dementia are:

- A positive nurse attitude towards ageing.
- Reducing noise within the environment.
- Placing familiar objects near the person with dementia's bed.
- Orientating the person with dementia to the ward and their immediate environment early after admission.
- Ensuring basic care needs are met, such as nutrition, fluids and toileting needs.
- Encouraging self-mobilisation.
- Uncluttering the environment.
- Using appropriate interior colours.
- Lowering signage.
- Providing good lighting and minimising glare.

(Source: Cunningham, 2006; Hanley, 2004; Hospital Elder Life Program, 2000; Li et al., 2003; Pritchard & Dewing, 2001).

WHAT INCREASES BEHAVIOURAL AND PSYCHOLOGICAL SYMPTOMS IN THE HOSPITALISED PERSON WITH DEMENTIA?

Generally, hospital is a daunting place for any person being admitted, inciting a level of anxiety in all of us. For the person with dementia this is certainly the case, with the design of the hospital posing the first challenge.

Firstly, the façade of an acute care hospital can appear large and institutional, containing many corridors, large numbers of people and multiple exit signs. All of these factors have shown to increase agitation in a person with dementia (Flemming & Purandare, 2010).

The odours and noises experienced within acute care can also impact on information processing, which leads to increasing confusion and agitation (Hanley, 2004).

Other contributors to a negative care experience for hospitalised people with dementia increasing confusion, agitation or aggression are:

- Increased communication problems between the person with dementia and their caregiver.
- Restraint use.
- Fatigue.
- Changes in routine.
- Changes in care giver.
- Moving wards or beds.
- Care giver demands that exceed functional capacity.
- Unmanaged pain.

(Borbasi et al, 2006; Frazier-Rios & Zembrzuski, 2005; Price et al, 2005; McCloskey, 2004)

INITIATIVES TO IMPROVING HOSPITAL-BASED DEMENTIA CARE IN AUSTRALIA

Dementia is an Australian Government National Health Priority. This has heralded an era of governments committed to increasing the quality of care people with dementia experience in our hospitals.

Some of the national and state funded projects that will impact on the quality of care of people with dementia while hospitalised are:

The Hospital Dementia Services Project (HDS Project)

This innovative study was funded by the National Health and Medical Research Council (NHMRC) and explored how hospital-based aged care and dementia services influence outcomes for people with dementia who used a public hospital.

Although findings of this project are based on NSW data, it is the first in-depth Australian study that captures empirical evidence to truly describe the state of care for people with dementia who are hospitalised. It will therefore inform decision makers on acute care improvements. Findings from this study were published by the AIHW (2013) in a report *Dementia Care in Hospitals: Costs and Strategies*.

SA Health Services Plan for People with Dementia (and Delirium) 2014-2018

The SA Health Services Plan for People with Dementia (and Delirium) 2014-2018 was developed by the Older People Clinical Network. The Network includes clinicians, consumers, care providers, health service managers, non-government organisations and researchers who work together to bring about best practice when providing for the health and welfare of older people across South Australia.

This service plan describes reforms that may assist competent care of people with dementia (and delirium) and centres around three themes:

1. Identification and assessment.
2. Seamless care transitions.
3. Effectively managed.

The plan expresses the need to implement the New South Wales Central Coast Local Health District social history tool called the TOP 5 (refer Reference below) into the acute care admission process. The network also plans on developing a dementia (and delirium) care competent clinical pathway and a dementia care competent pathway at End of Life.

Confused Hospitalised Older Persons (CHOP's) project – Agency for Clinical Innovation, NSW

In 2011, the Agency for Clinical Innovation, located in New South Wales, commenced the Care of the Confused Hospitalised Older Persons Study. The study aimed to develop a systematic approach to the identification of older people with confusion in hospital; the investigation of the causes of confusion and the implementation of effective treatment and management strategies.

The study was funded by the NHMRC and was trialed successfully in five New South Wales hospitals. This program involves seven key principles:

1. Cognitive screening.
2. Risk Identification and prevention strategies.
3. Assessment of older people with confusion.
4. Management of older people with confusion.
5. Communication processes to support person centered care.
6. Staff education on caring for older people with confusion.
7. Supportive care environments for older people with confusion.

Dementia in Hospital Program

The Dementia in Hospital Program was developed by the Ballarat Health Services.

The program utilises a cognitive impairment identifier located by a patient's bedside to inform staff that the patient may have a dementia, delirium or other cognitive impairment and for the staff to engage in caring for their special needs.

The program was trialed in the Ballarat Health Services and further trialed in five other Victorian based public hospitals.

Evaluations on the use of the identifier, together with education on caring for a patient with cognitive impairment, were positive in making a change to care outcomes of people with cognitive impairment by increasing staff knowledge and satisfaction (Ballarat Health Services, 2004; Foreman & Gardner, 2007).

In November 2014, the Central Adelaide Local Health Network in South Australia was selected to roll this program out in 2015 through the Royal Adelaide and Queen Elizabeth Hospitals.

Based on a presentation by Lesley Habel at the Hospital Care for People With Dementia forums

Lesley Habel was an Acute Care Researcher and Dementia Educator with Alzheimer's Australia SA. She undertook an evaluation of the Dementia Behaviour Management Advisory Service (DBMAS) within acute care and developed a mentoring program currently being rolled out in several South Australian hospitals.

Lesley also facilitated and re-designed a medical student program on dementia awareness. She was driving an e-learning End of Life Dementia Care project within the Dementia Training Study Centre (DTSC).

THEMES

Understanding the Impact on the Person With Dementia

- Ensure a detailed social history, preferences, likes and dislikes of the person with dementia is taken.
- Acknowledge that the recovery time by the person with dementia from the hospital experience is often lengthy.
- Treat the person with dementia with dignity and respect.

Carer Recognition

- Lack of recognition of the role of the carer, in particular in Power of Guardianship, Advance Care Plans, duty of care.
- Lack of appreciation of the knowledge and insights that the family carer has about the person with dementia.
- Understanding of carer needs.
- Having emergency respite care plans in place should the carer need hospitalisation.
- Consider the cost to the carer of being with the person with dementia, especially for country people.

Hospital Avoidance

- Social isolation in the community results in increased vulnerability that feeds into more emergency admissions.
- Community support: supportive neighbours can minimise hospital admissions.
- Accessibility to GPs at an affordable price.
- Specialists / paramedics to visit residential aged care facilities.
- More beds in residential aged care facilities.

Planned Admissions

- Lack of planned admissions, which are predominantly due to an emergency.
- Reports of hospitals refusing to accept people with dementia.
- Need for the family to have pre-admission documentation in case of a hospital visit.

Appropriate Discharge

- Consider the needs of the person with dementia and their families regarding time of discharge.
- Discharge planning from the time of admission for appropriate care and support during the hospital stay.

The Hospital Journey

- Better planning for the hospital experience as a journey from pre-admission, through admission, the hospital stay itself, discharge and post-hospital care.
- Family access to people with dementia twenty four hours day, to help them settle and to advocate for them.
- Staffing levels and paperwork keep staff from caring for patients.
- Long waiting times for procedures increases agitation.

Access To Dementia Champions

- Trained staff or volunteers to guide and support the person with dementia through the admission journey, to help to maintain calm and settle agitation and to advocate during the hospital stay.
- A Dementia Liaison Officer to be accessed at point of admission and have regular contact throughout the hospital stay.

Reduce Waiting Times

- People with dementia are being left alone and/or unattended in Emergency Departments.
- Make people with dementia a priority in Emergency Departments.
- Long waiting times for any treatment in the hospital increases confusion and agitation.

Staff Dementia Education

- Insensitive staff.
- Staff have limited understanding and knowledge of dementia and associated behaviours.
- Lack of dementia training amongst staff (including the needs of carers).

Dementia Friendly Environment

- Hospital environments are not dementia friendly (poor signage, noisy).
- Emergency Departments are a place of fear for people with dementia.
- Need for secure dementia specific wards and units.
- Requires large, clear signage including pictures (eg toilet).
- Limit multiple moves from ward to ward whilst in hospital.
- Dementia champions in every hospital who assess and make recommendations.

Communication

- Lack of communication amongst staff, between community facilities and hospital services and between staff and people with dementia and their families.
- Communication can be impacted by different accents. Consider electronic case notes.
- Need for dementia identification on case notes and by dementia identifying wrist bands and/or a dementia friendly symbol by the bed.
- Cultural differences exacerbate communication difficulties.

Medication

- Issues with inappropriate medication and over prescription (chemical and/or physical restraint).

CARER STORIES

A LONG AND DIFFICULT JOURNEY

Options

My husband is in his mid-80s. He has Alzheimer's and has been in residential care since June 2013. He is quite mobile. He spends a lot of time walking.

Earlier this year he started having episodes of unconscious collapse. The first time it occurred I elected not to send him to hospital thinking that it may be a one off event. On the second occasion an ambulance was called and on arrival they assessed him so that a more informed decision could be made about whether he needed hospitalisation.

The ambulance officer making the assessment said that his collapse appeared to be cardiac related and that it was possible that he might need a pacemaker. I elected to send him to hospital, as this is the only way that this type of assessment can be achieved.

My primary concern was his physical safety. If medication or undergoing a simple procedure would allow him to continue to maintain his mobility safely, then I wanted him to have that treatment option.

Access to Acute Care

The choice of hospitals is limited depending on the presenting problem. FMC was the nearest appropriate facility, which is where he went.

Medical Care

On my husband's first admission, he was assessed in the Emergency Department and then admitted. He was transferred to a ward in the evening and assessed again. The following day he was seen by different doctors. They then decided he should be transferred to a different unit so he waited until the next day when he was seen by yet another team.

Each time he was seen by a different doctor it seemed to be necessary for me to repeat his whole history. Each doctor had a different opinion on what investigations needed to be done. The end result was that very little was done.

His second admission followed a similar course.

None of the doctors on these two admissions requested a cardiac consult. The general impression given was that my husband should not be there.

One doctor suggested that he was probably just having a nap and that the staff at the aged care facility really had no idea what they were doing. Another doctor, when I expressed my concern for my husband's physical safety, asked me why he was in an aged care facility if he could walk.

On my husband's third admission, he was seen by an Emergency Department consultant. I believe this was because he was presenting for the third time in eight weeks with the same problem.

"This consultant was excellent. He LISTENED to what I had to say. He HEARD what I had to say. He understood WHY I kept bringing my husband in."

He agreed that it was reasonable to have a cardiac review and find out what treatment options there were that would be appropriate for my husband. He outlined this plan in my husband's record and arranged for him to be admitted at 10pm. As there were no beds available my husband remained in the Emergency Department.

When I arrived at 10am the next morning, the medical staff had already done their round. When I requested to see one of the team I was told that they were too busy to see me that day. I checked with the nursing staff to see if a referral had been made for a cardiac consult. It had not. I asked them to contact the medical team again to see if they would speak to me by phone. They would not.

In total frustration and despair I went and had a coffee with a friend who is a senior member of the nursing staff. I then went back to my husband in the Emergency Department where he was still waiting for a bed in the ward.

Shortly afterwards the nurses came and told me my husband was being admitted to Coronary Care, twenty four hours after arriving in the Emergency Department. His admission to Coronary Care only occurred because of a little help from a friend in a senior position.

Immediately everything changed. The medical staff could not have been nicer. They listened to my concerns and issues and discussed my husband's presenting problem, my desired outcome for him and possible treatment that would be suitable for his situation.

As a result my husband was fitted with a pacemaker because there was a strong possibility that it would resolve his problem.

So far my husband has not had any further events. When he went for a pacemaker check after four weeks, it showed that his pacemaker had been activated 53% of the time.

Nursing Care

Over the three admissions my husband spent fourteen days in hospital. Some nursing staff were very good, but many had little idea how to manage patients with dementia. He was kept in bed because it was more convenient for the nurses, not because he needed to be in bed.

On the first two admissions he was moved from ward to ward and from room to room. This was largely due to bed pressures but resulted in an exacerbation of his confusion, dislocation and behavioural issues.

Summary

While the outcome has been good, the journey was long and difficult. I believe many carers would not have made it to the end.

"I was ultimately successful only because I know the public hospital system well, was determined to get the assessment I believed my husband needed and had some inside help to move things along."

AGITATION, CONFUSION, DISORIENTATION

My mother is in a nursing home and had to be transported to hospital. The ambulance staff were great. She had a C-Pap machine attached and was experiencing heart failure. I went in the ambulance with her. Everything was handled very quickly in the Emergency Department.

All the time I explained to both the ambulance staff and emergency staff that my mother had dementia, and that she may not communicate. In saying that, Mum made more sense that day than she has for a very long time. She did tell us when she was in pain.

In the Emergency Department it was decided that she needed a catheter. A male nurse fitted the catheter with no explanation to my mother and I practically assisted him doing the procedure. My mother is a very private person and was very upset at a male nurse doing this procedure.

Mum was kept in the Emergency Department for as long as possible before going to a ward. It was explained by one doctor that she would get better one on one care in the Emergency Department and that it would go downhill from there in a ward.

We then tried to explain to nursing staff Mum would get very agitated and confused. One staff member was very good and did assist as much as she could. Of course, Mum did not know what the catheter was and always wanted to get up to go to the toilet.

We spent hours with her trying to calm her down. Medication was used to calm her. The next day we were told that medication was given at 1.00am to calm her down again and that she was not waking up in the morning. Obviously too much medication was given.

The following day, Mum was up and about and wanting to leave the ward. The staff decided going back to the nursing home would be the best result for everyone. On returning to the nursing home Mum was confused and disorientated for nearly a week.

"I know that the hospital system does not have the staffing to cope with people with dementia and it would be great if something could be done about this."

KEEPING PEOPLE ALIVE

My husband broke his hip and femur a few weeks ago and had pneumonia and a UTI simultaneously. He was placed in a ward for stroke patients.

We had to make terrible decisions. He was moved to the Repat temporarily but although he was dying, they operated on the hip and femur at FMC with a 30% recovery rate. They also wanted to feed him artificially which I refused. He died two weeks later.

My husband had several doctors at FMC who were intent on curing the bit of his body that interested them, but there was no holistic approach. I said I didn't want him to suffer more because he had no quality of life prior to the fall, he had not been able to communicate for four years and he couldn't walk. The response was "our job is to keep people alive because relatives might sue us if we don't." I said "I won't" and the response was "But your son might".

"I get the impression from hospitals and nursing homes that the fear of civil action is now the focus that determines treatment."

Needless to say I had Medical Power of Attorney and my husband had a legal document indicating no intensive treatment if the quality of life had gone. That was ignored with arguments about definitions. Bear in mind that their definition of 'no resuscitation' would be very different from that of the patient.

HOSPITAL NOT "GEARED UP"

My wife went into hospital for a cancer operation. The hospital was definitely not geared up for processing or identifying or spending time with a person with dementia. A lot more is required of a person with Alzheimer's.

The nurses seemed not to have the training or inclination. The nurses just shouted at people in the hope that they would respond. The situation came across as people having apathy and a lack of information.

I put up a sign that my wife, the patient, had dementia and could not speak, feed herself, take food by herself: "Please help me".

"I got rotten with the nurses because I felt they were treating her as an interim person. I straightened a couple of them up."

I sat with her all day until 10pm. I did all the feeding and toileting. The staff didn't like that. I felt like they treated me as if I had no authority. I wanted to give my wife her medications and the staff objected to that. I did not know half the time what they were giving her. They were sloppy about medication.

Even her GP did not know the medication the hospital was giving her or the information they were using. The information did not appear to have been updated on their computer regarding medications or whether the doctor was available.

No one looks into the chart. She was just another patient. Staff did not understand the complication of Alzheimer's. They told her, "You can go home now".

Not a Choice

Every day is a new day. Medications is the first thing I think about. In hospital they said that she had an eating problem. No she hadn't; it was a nurse problem. I spent an hour and half at dinner time with her.

"It is something you have to do; you don't have a choice. You need to go in yourself."

CONFUSION AND ANXIETY

Father was taken to the Emergency Department with mum via ambulance following a fall at home. The ambulance personnel did not advise which hospital the patient was taken to.

No water was available. At the time of the fall he soiled himself. This was attended to at the hospital four hours after the fall when we finally insisted this be done.

Dad had X-rays and scans for neck injury, heart attack or possible stroke in an eight hour period. He received one meal during this time but no water when requested.

"There was confusion and anxiety for dad."

Dad remained in hospital for four days before returning home.

WAITING

Preparing my wife for breast cancer operation we had to be there at 9.30am with no breakfast pre-operation. Her memory is such that if she needs to go to the toilet in a strange area I have to be there to meet her as she gets lost. We had to wait four or more hours. We were hungry and she was getting impatient and upset – wanted to go home.

Her daughter tried various ways to 'entertain her'. Eventually she had to wear the hospital gown.

She wanted to put on her clothes and go home. We had to walk her to see the pictures hanging on the walls, then go back to sit and wait again.

"Waiting a long time."

Then her daughter pressed the red button and a nurse came. We told her our problems, that my wife was bored, wanted to get dressed and go home.

Finally the time came to go for the operation. We got her to the operating area and explained she was going to have a breast cancer removed. She had to be sedated to relax her.

I have heard of a relative who had to wait 12 hours for an operation.

DUTY OF CARE

My mother was put through unnecessary assessments when I was clearly able to provide the information. The issue of duty of care was raised by a health professional.

"The first duty of care for any health professional is to respect the rights and autonomy of the person living with dementia, even if that can only be expressed through a primary carer."

I am and have always been concerned about what gets disguised as necessary behind those three words 'duty of care'.

My concern is that people living with dementia are denied their rights and often put through unnecessary assessments or treatments that anyone else would not be put through, even when a loved one is present and able to provide information or has substitute decision making powers and is articulate enough to stand their ground.

Denying rights under the guise of duty of care is indefensible."

TIME

From a Social Worker's point of view, having worked on a ward with clients who have Behavioural and Psychological Symptoms of Dementia (BPSD), the amount of work expected of a single person employed in health is an OH&S issue, not just for the Allied Health Professional, but for the parties they have a duty of care with.

Funding to health and the public service in general is being reduced and withdrawn, causing risk of harm to Allied Health and patients.

When I worked on the ward I did not have time to eat, drink, go to the toilet, think about how to approach problems carefully and rationally, or even see dementia clients to talk to them about discharge plans and treatment options.

I feel more resources need to be injected into health in terms of workforce size to reduce the risks of mistakes, to reduce OH&S issues for staff, and to be able to provide a compassionate response to patients rather than a reactive processing response that is automatic and not thoughtful.

DISCUSSION

GOING TO HOSPITAL: PRE-ADMISSION

PERSONAL STORIES

Participants observed that, in general, hospitals were not designed for people with dementia. The hospital experience, from going to, getting into, staying at and being discharged from, was a long and difficult journey for them.

HIGHLIGHTS

- Hospitals refusing to accept people with dementia.
- Lack of information about the person with dementia.
- The stress of being in the Emergency Department environment.
- Poor communication with family.
- Reliance on the person with dementia for information about their health concerns.

Getting There

Participants outlined a lack of communication about which hospital family members were being taken to, as one participant related,

“Mother has been to hospital twice in twelve months with a broken hip. The first visit she was taken in the car and admitted by father. The second time she was taken by ambulance and already knew where or what hospital she was taken to. Maybe a written note from the ambulance to say where and a contact number.”

Another spoke about a four hour wait for an ambulance in regional Victoria for her mother with a broken arm who was considered ‘non-urgent’, even though she was 90.

One woman always escorted her husband to hospital for any admission.

On Being Admitted

Participants spoke about their experiences with being admitted to hospital. These included private and some public hospitals refusing to accept

‘complex dementia’ patients, the person with dementia not being admitted ‘due to being a wanderer’ and no available beds.

The wife of a man for whom admission had not been arranged, even though it had been agreed to for respite and an ACAT assessment while she had her own medical issues attended to, reported that she was so upset that she drove her husband to the hospital and left him there to be admitted.

Another example was of an 82 year old woman who was moved four times before her admission. This caused her “enormous agitation and anxiety”.

The Emergency Department

Participants observed that most people with dementia enter hospital because of emergencies rather than having a planned hospital stay.

However, long waits “without support”, a disruptive “chaotic, confronting” environment and the “high stress” of being in Emergency led to increased confusion, anxiety and agitation on the part of the person with dementia:

"My step-mum was taken to Emergency after a bad fall. Nothing was broken but she was very badly bruised. The Emergency Department was busy. She was left on a gurney for twelve hours in a passageway. They observed her at intervals regarding the fall but she could have easily wandered off. She was very confused. There was no family member who could stay with her."

"You become a number. The signs that are up are not dementia friendly."

"My mother with Alzheimer's was admitted to the Emergency Department very frightened, unable to communicate what was wrong."

One participant observed staff as having "no communication skills for a person with dementia; for example when checking consciousness they asked, "Do you know where you are?"".

One woman who found her GP "very unhelpful" decided to take the person with dementia to emergency "to get her admitted to see what was wrong", but after waiting twelve hours and being told her situation was not life threatening, she "gave up and took her home".

Another reported that staff checked her husband for drug injection sites, which he found "very distressing".

Managing Well

Carers also spoke of "good experiences" when people were processed quickly and when residential aged care facility and ambulance staff manage the patient well:

"Trained paramedics managed to keep him calm and advocated for his speedy treatment. He was processed quickly in Emergency Department, with minimal staff with a calm, quiet relaxed environment."

Impact on the Person With Dementia

One participant reported that her mother who had Alzheimer's experienced a panic attack at home on her birthday due to too many phone calls. Her mother could not describe what was happening. The family thought it was a heart attack. She was taken to hospital by ambulance which was a very frightening experience.

In the hospital many tests were performed. Although the participant's mother was discharged the next day, it took many days for her to recover from that experience.

Information on the Person With Dementia

Participants expressed concern at the often lack of information that hospitals had about the patient with dementia. The information lacked the "social history of the person's likes and dislikes and carer recognition".

They were also concerned at "the heavy reliance on reporting by the person with dementia".

Relationship With Family and Care Workers

Participants expressed concern at poor communication between hospitals and the person with dementia's family.

In one example, medication doses were doubled despite the family requesting that it not be. It was reported that the health professional did not listen to the family carers regarding the regular dosage. The person with dementia became agitated, non-verbal and "like a zombie" at which stage the drug was withdrawn.

In another case, the carer reported the failure of the hospital to notify family members who could have assisted by going to the hospital. Although a message was left on message bank, the carer felt that not enough effort was made to try to contact family members.

Other examples included hospital staff not listening nor following the instructions of guardians or carers and paramedics; of a 74 year old man who lived alone with dementia being admitted three times, but the hospital not informing the patient's family of his whereabouts; families being expected to provide information on admission which they may not be able to fully articulate, especially when feeling stressed, and the difficulty for the carer to find the patient when they have been admitted by ambulance.

One In-Home Care Worker spoke about a client who was in her 40s. Whenever she went into hospital, the client's medical file was never checked. There were important instructions on the front of the medical file and these were never read, so the same instructions had to be issued over and over again.

Private Hospital Refusal

Participants were concerned at reports that private hospitals were refusing admission to people with dementia:

“Even though I had paid for private health top cover for thirty five years, my husband was rejected at two hospitals because he had dementia. I was told that he would need a carer to stop him from wandering and the hospitals could not afford to provide one. I was then told that none of the private hospitals took patients with dementia so I stopped private health cover.”

“My husband has private health cover and could have been admitted to a private hospital from the FMC Emergency Department. He had three admissions for the same problem in two months. Each time he was refused admission to the private hospital because of his dementia.”

WHAT NEEDS TO BE DONE?

The ideal approach to care for someone with dementia in hospital is for a dementia liaison worker to start the journey with the person and ensure they have adequate support and appropriate care during their hospital stay (Alzheimer’s Australia (2014).

Consideration needs to be given for the complex needs of people with dementia from socially, culturally and linguistically diverse backgrounds, for example those from Culturally and Linguistically Diverse, Aboriginal and Torres Strait Islander, Lesbian Gay Bisexual Transgender and Intersex, Veterans and Homeless communities.

HIGHLIGHTS

- People with dementia given priority for admission and in the Emergency Department.
- Collect information on the patient prior to admission. Alternatively, have this information on hand in case of an emergency admission.
- Improved staff knowledge and understanding of dementia and associated behaviours.
- Recognition of carer knowledge of and expertise about the person with dementia.
- Improved hospital avoidance programs.

“The doctors need to listen to the person and not think “here we go again, another story”!!!”

The GP

Ideas to improve the relationship between the GP and the hospitals included having GP clinics attached to hospitals and the GP faxing ahead a letter to the Emergency Department.

A particular recommendation was for GPs to provide the person with dementia and their families with a medical file which included the primary diagnosis of dementia, medications, medical and personal history and a list of preferences.

This would minimise errors and missed information, limit the need for repeated questioning and inform hospital staff of the best way to relate to the person with dementia.

Getting There

Participants outlined the need for a support person to accompany the person with dementia when they went to hospital. Ambulance personnel needed training for assessment and prioritising a person with dementia.

They recommended that a social worker visit the patient in their home prior to admission, to assist the person with dementia with their preparation.

On Being Admitted

Participants wanted to see patients with dementia become a priority in the admission process. Questions about dementia and diagnosis, rather than being far down on the Admission Sheet as at present, should be at the top with an "ALERT" sticker.

Participants recognised that with a planned admission a person's needs could be identified more easily. As this was not the case in emergency admissions, identifying the needs of the person with dementia must be done at time of admission to the Emergency Department.

Often, however, important information about the person with dementia was missing, or went missing, resulting in the same questions being asked "over and over again".

People with dementia needed a small, quiet, private pre-admission area while waiting; "maybe a Memory Reception Area" as one participant put it.

Participants wanted staff to be made aware of the dementia on admission, to take time to talk to patients with dementia, to keep the person with dementia being informed of what was happening on an ongoing basis, as a matter of respect. There was the suggestion that this might be a role for volunteers.

They recommended that hospitals had a Dementia Liaison Officer that patients and families could access on admission and have regular contact with throughout the hospitalisation.

Information About the Person With Dementia

Participants spoke about the need for the hospital to be given information about the background of the person with dementia. This included personal history, Advanced Care Directives, their likes and dislikes, things that would increase or decrease their anxiety, such as being touched or how they might cope with noisy, busy environments like Emergency Departments, strategies to help the person with dementia (eg keep information simple, repeat things, reduce noise, regular toileting support) and medical records and community assessments.

Of particular importance was information about the medications being taken at home, to ensure that the same were prescribed in the hospital:

"The information should be passed on to relevant people so you are not rehashing the same thing all the time (eg to anaesthetist, radiographer etc)."

There was a need for medication and history to be written down on any reports; that MedicAlert bracelets and alerts regarding allergies were given due attention.

The carer could take any written information such as medications, history and previous hospital discharge letters with them when they accompanied the person with dementia to the hospital.

This information needed to be provided in advance if possible by the person with dementia and/or their carer or the residential aged care facility.

Participants recommended that a dementia champion or carer went to the person with dementia's home or residential care facility to view how they lived, how the bed was set up in the room in relation to the toilet, how they had their meals, how they slept; to be able to clearly communicate to the hospital staff "the little things".

"The individual peculiarities are most important."

The Emergency Department

Forum participants wanted Emergency Departments to be more dementia friendly. They wanted hospitals to consider the impact of the Emergency Department environment, the long waiting times and the multiple bed transfers on patients developing delirium.

A better understanding of the dementia patient regarding their state of mind would include treating not only the medical condition, but the dementia as well.

Becoming dementia friendly would include establishing dementia friendly specific areas in Emergency Departments, people with dementia being seen and processed quickly in Emergency Departments, assessment prior to admission, access to specialist and liaison nurses and a reduction in stimulation to limit agitation. Participants were supportive of the use of the TOP5 initiative to prevent agitation developing.

A dementia worker in Emergency Departments "would be great as a dementia champion to demonstrate dementia care to the staff as a supernumerary person on the ward".

Staff Understanding

A carer asked, "If paramedics are trained to manage agitated behaviour, why cannot the Emergency Department and hospital staff know more about dementia?"

Participants wanted trained dementia professionals in Emergency Departments, as well as better education for nurses and doctors overall regarding the basics of patients with dementia and dementia care, including training on how to take personal and medical histories, that is, asking the right questions at emergency and other admissions.

One carer noted that since some staff were "not suited to work with dementia, let them work somewhere else".

Relationship With Family and Care Workers

Families sought recognition: acknowledgement of their expertise and the importance of carers sharing their information about loved ones.

They wanted hospital staff to take the time to listen to family carers and guardians, to use the knowledge of the family and carer and to not assume that the person with dementia could not be looked after at home by the carer.

They wanted persons with Enduring Power of Guardianship to be respected and heard before medical and hospital staff made assumptions or contacted persons who have no authority on decision making.

Carers with Advanced Care Directives in place were concerned that others should have them prepared and that they were communicated effectively in the hospital.

Carers sought support and education towards the carer needs. They wanted hospital staff to understand the need for appropriate, well informed communication about what was happening, the problems concerning the patients with dementia, the treatment and the progress toward discharge.

Carers may feel exhausted but guilty. They may find it difficult to relinquish care and control. They may even complain that the care is not to a standard that they would expect.

Family members wanted to be able to remain with the patient if they were able to. They reported that a positive experience for the person with dementia relied on the family being present twenty four hours a day.

The carers encouraged each other to have information about the person with dementia, for example personal stories, likes and dislikes, so that they could advocate for them. It was recommended that people prepare an information package for emergency admissions "just in case", because "under stressful situations people cannot convey important information".

Such a package could be similar to the medical file requirements for older adults travelling abroad, with a similar template developed for people with dementia and made available to families to carry at all times. This would require the education of GPs to instigate the process.

It was also recommended that carers have emergency respite care plans in place in case the carer needed to go to hospital.

Hospital Avoidance

In exploring the issue of hospital avoidance, participants recommended the establishment of Intermediate Care Units that people could go to before hospital, for GPs to refer people with dementia "to Memory Clinics, physiotherapists and OT for functional assessments etc which may minimise the need to be hospitalised".

They wanted residential aged care facilities to introduce better systems of review to assess the suitability for admission and to prevent unnecessary hospital transfers and admissions.

Possible roles for paramedics included them being called to review residents in residential aged care facilities before making a decision to send them to hospital and people with dementia "being treated at home by ambos rather than going to hospital".

Hospital avoidance programs could be increased by better support for people at home. A friend looking after a neighbour or a 'volunteer guardian angel' looking after a person with dementia, keeping them at home, was regarded as hospital prevention.

Another recommendation was for an emergency twenty four hours a day contact to talk through the problem before a decision was made to send a person to hospital.

THE HOSPITAL STAY: MAKING HOSPITALS SAFER FOR PEOPLE WITH DEMENTIA

PERSONAL STORIES

Being admitted to hospital can be a confusing and frightening experience for most people, but more so for a person with dementia. Cognitive impairment and difficulty communicating within a busy hospital environment can potentially lead to poorer health outcomes and greater risk of adverse events (AIHW 2013).

HIGHLIGHTS

- Confusion, distress and panic by people with dementia during the hospital stay.
- Staff with limited knowledge and understanding of dementia and associated behaviours.
- Time pressures on staff.
- Carer knowledge of the person with dementia and carer needs are not taken into account.

Impact on the Person With Dementia

Participants observed panic, distress and violent agitation amongst people with dementia in hospital.

People with dementia became confused due to “phones ringing, people everywhere, shift changes, lots of doors and colours all the same. Hospitals are very confusing. It is easy to get lost. There are not enough signs and it is not easy to read layout”.

Carer stories:

“Due to a spinal anaesthetic, when the patient woke up post op he couldn’t feel his legs and panicked. He needed more support. Having his wife present post theatre would have helped. He was very disorientated. Talking to his wife on the phone helped him settle. He needed an advocate to protect his wellbeing.”

“While at hospital she wandered away many times. One time, when she was looking for family she got out of the hospital.”

“My friend’s mother was admitted to hospital last year. First she was moved in Emergency Department four times, then she was moved to the ward. She needed to go to the bathroom and was told just to wet the bed. She was finally discharged at 2.00am with just her night dress.”

“Dad got distressed thinking his belongings had been stolen. He’d forgotten that he’d placed them in the hospital safe deposit during his admission. He needed reassurance from staff that his belongings were safe, but unfortunately no one clarified this with him or with mum.”

“Dad was transferred to the secure dementia wing of the hospital totally confused and wanted to go home.”

“There was excessive and inappropriate administration of Haloperidol. The patient became violent and agitated despite the family asking for that drug not to be given.”

“A relative will take directions but ‘reacts’ to touch in a negative way. If not ‘crowded’ they could be managed. Having a trained volunteer as a ‘companion’ would work well.”

Participants observed that the diagnosis of dementia may be noted; however, how that was addressed and acted upon may be a different matter.

Participants spoke about the impact of the lack of family support, inappropriate mobility support and the lack of understanding regarding reasons for the exacerbation of behaviours. There were issues with information being provided verbally to a person with dementia.

They spoke about people with dementia who “may not eat their meals if they cannot feed themselves and have difficulty opening packets with trays placed too far away”.

“All meals given were not pureed, even though this was noted on the file and the card above her bed. Mum needed assistance from a family member to eat.”

There was an example of a person being given a diagnosis of dementia whilst in hospital, without family members being present. This was “very upsetting for him, with no support”.

Participants reported people with dementia who “felt like they were imprisoned, couldn’t move around freely”.

Carers felt under pressure to get the patient out of the hospital, as if “the patient was not welcome”. One carer felt that the staff thought that their relative was a nuisance.

Time

Participants observed the pressure for procedures to be done quickly. Carers had to “strongly advocate for more time to think about the issues: hospitals are very clinical”.

Another observed that there were times “where help was needed but nobody was available, not just for dementia but other medical conditions”.

Excessive times waiting for surgery whilst in pain was also a concern. A three day wait was one example.

Staff Issues

Participants were concerned about staff who did not understand dementia, who were “controlling” with “no time to meet everyone’s need”, who made carers sometimes “feel as if they did not care” and whose style of communication “could sometimes be abrupt”.

Cultural differences could undermine communication and care support.

Consumers expressed their annoyance at staff that asked, “Do you know where you are?”

There was also concern that staff were “run off their feet”.

Impact on the Family

Carers in particular expressed their distress at their needs not being met, or their concerns being ignored with respect to appropriate treatment for the person with dementia:

“A 70 year old man with Alzheimer’s was admitted. He did get an ACAT assessment whilst an inpatient. Health professionals treated the carer (wife) like dirt under the broom and did not respect her opinion and lived knowledge of her husband as his carer and wife.”

Families could not “assume that staff knew what was going on: you have to start from the beginning every visit, every shift, advocating for the patient”.

They were also concerned that “the wrong information could be written down”.

Carers spoke about the cost of staying with the family member, particularly if from country regions or interstate:

“These costs are not covered by health funds. Some private hospitals do charge and don’t provide meals etc, so staying can be a big cost to families even though their presence can reduce Behavioural and Psychological Symptoms of Dementia.”

Carers reported “nurses not doing their job and relying on family members to do things for the patient”, “when the carer is in the hospital it’s difficult to get help for the dementia patient”.

Participants observed that staff often appreciated the help from family members but that hospital policy did not always encourage this help to take place.

Being There Is Not All bad

There were participants for whom the hospital experience “overall was quite good”, where “medical and nursing staff were generally good”.

WHAT NEEDS TO BE DONE

Sustained commitment and leadership from policy makers, senior management and healthcare professionals is essential if we are to achieve the cultural change that is required to improve the outcomes for people with dementia in the acute hospital setting (Alzheimer's Australia 2014).

HIGHLIGHTS

- Provide an alert by the bed of the person with dementia, for example, a dementia symbol.
- Improve staff knowledge and understanding of dementia and associated behaviours.
- Work closely with family and carers.
- Develop standard procedures in caring for people with dementia.
- Make dementia care a speciality field.
- Provide specialist dementia wards or units in hospitals.
- Provide dementia champions in every hospital to assess needs and make recommendations.

Impact on the Person With Dementia

"Glad to hear that hospitals are getting up to speed – dementia CARE is a speciality field like chronic diabetes, mental health."

The Physical Environment

Participants recommended the establishment in hospitals of dementia friendly units, or at the least, to make sure that the hospital environment met the needs of people with dementia.

This would include an assessment of whether a person can use the call bell.

There should be larger signs and pictures showing the toilet, with a regular toilet schedule. It was important "to make sure the floors in the toilets are clean, especially in the night time as falls can occur and you are not very popular!"

Visual prompts indicating where the person was and the time would be helpful. Where possible, a quiet, relaxed and welcoming environment needed to be created, with quiet, private areas, places to go and outside spaces.

Participants recognised that it may be difficult due to medical issues (eg may be in hospital for cardiac issues or fractures from falls etc) to have secure areas for people with dementia. In that case, they recommended that patients with dementia were located near the Nurse Station and that remote cameras be utilised to observe the patients with dementia.

Patients with dementia needed to be able to stay in the same room, or the same ward for the length of their hospital stay. Single rooms for privacy with a table and chair to eat at, a TV at the right height and a lounge to sit in away from bed would be helpful.

An alert by the bed could identify that the person had dementia. The example of one Adelaide hospital that used a system for general care needs: red for full care; orange for assist and green for minimal care, was cited.

"Dementia wards should be 'home' friendly."

The Person

Participants sought the recognition of the patient as a 'person' rather than a disease. Staff understanding of the different dementias would result "in a better understanding of the patient with dementia regarding their state of mind".

They recommended that patients with dementia have a form of ID, such as a coloured wrist band, including the bed and ward they are from, to alert staff that the patient had dementia and may be wandering and at risk

Participants sought greater interaction with patients with dementia in hospitals. They observed that people with dementia should not be ignored or left in a room alone. Staff could start by engaging with conversation, explaining rather than being 'physical'.

It was "the small things and common sense that really helped."

Patients with dementia needed to be assisted at meal times, shown their cutlery, with lids taken off containers. Packaged food did not make sense.

The proper management of patients with dementia included taking more time to understand what might be wrong, developing safe and supportive strategies that allowed them to do things that calmed them, knowing their reaction to touch, providing them with their own clothes, limiting choices or if necessary not giving a choice (within legal parameters) and having familiar items such as photos and blankets with them.

Support for people who don't have family who can visit would include volunteers who came in as companions to visit the patient with dementia and visitors to give people with dementia one on one friendly interaction.

Impact on the Family

Participants acknowledged the need to work closely with family and to recognise the role of carers for their care of loved ones.

Supporting carers included hospitals being more open to having family members stay, providing family facilities and meals etc without cost, so carers could stay with the patient with dementia twenty four hours a day and reassuring the carer that appropriate care is in place to allow the carer to be more at ease.

Single rooms were important in enabling family members to stay twenty four hours a day.

Health professionals needed training in treating the carers and families with dignity and respect, in acknowledging their superior knowledge of the patient over that of the professional.

Participants wanted hospitals to ensure clear communication strategies as to which family member the hospital should contact and how, when and who the family should contact at the hospital. One hospital had a carer support worker.

Participants wanted "suitable staff" caring for people with dementia. They observed that "some staff were more suited to this, by taking a slower pace for people with dementia, being gentler and understanding the triggers for aggression".

Time

Participants wanted a reduction in the waiting time between pre-operation and operation.

Staff Understanding

Participants wanted more education for all staff, including nurses, doctors and ancillary staff, to raise their awareness of dementia. They wanted this education to result in better recognition and understanding of dementia and the requirements for appropriate care for patients with dementia, for the best ways to communicate with people with dementia and how to de-escalate agitated behaviour. This would develop a safer environment and a decrease in Code Blacks and the use of chemical restraint.

This training would be ongoing throughout the staff's career. It would include stories from people who are caring for someone with dementia, or who have looked after someone with dementia.

Patients with dementia needed someone with specialty training to liaise between the patient, their carer, the nurses and other staff and not to focus just on what the person with dementia was in hospital for:

"Even one person per shift, for every shift, would help."

"Hospital staff that know how to treat clients with dementia PLEASE."

Being There

Participants recommended the development of standard procedures on the care of patients with dementia, which all staff would use. These would include both verbal and non-verbal approaches, for staff to introduce themselves every time they went to see the person to ask and record how the patients wanted to be addressed, to document and communicate the dementia diagnosis and health issues across all areas and transfers and to avoid or reduce multiple bed transfers.

Participants wanted these standard procedures to be policy guidelines consistent between hospitals.

Resources for staff would include Memory Hub resource libraries in hospitals and the use of the TOP5 initiative.

It was also suggested that there be monitoring of the people who have access to the patient with dementia.

Participants said it was important to keep communication open with the family, to keep the language simple, to listen to carers in understanding the needs of the patient and for families to be contacted to be available for meetings with doctors, especially when being given bad news.

They recommended the use of a communication book to be routinely given for all patients, with staff and families educated on its use.

Symbols

Participants were supportive of the dementia symbol being developed by Alzheimer's Australia. This was regarded as a "great idea" that should be on a board behind the hospital bed with a list of important information underneath it, for example, other health conditions such as diabetes, what the person always needs in personal likes and dislikes.

Other

Carers asked that in cases where there might be a doubt about the diagnosis of dementia could this be confirmed or clarified during the hospital stay.

"Showcase better dementia care in hospital: what are good examples and models?"

GOING 'HOME': DISCHARGE TO WHAT?

PERSONAL STORIES

Whatever 'home' a person with dementia might be going to on discharge, participants observed that limited planning and support created a new set of difficulties for post-hospital care.

HIGHLIGHTS

- Going 'home' means what?
- Inconsistent discharge processes.
- Inappropriate timing of the discharge.
- Limited communication with, and support for, families, facilities and services regarding post-hospital care.
- Post-hospital disorientation by the person with dementia.

Going 'Home'?

Whilst the hospital might be "keen to release him ASAP to either a nursing home or home", in many instances going 'home' on discharge, often meant to a different place, a new 'home':

"Going home may be to a relative if the person is unable to cope on their own. This added to their confusion as they were not in their own environment."

"My mother had two hospital stays during her dementia journey. Despite having a supportive family capable of caring for her at home, the recommended course on both occasions was to move her into residential aged care."

"He seems to be permanently in the Repat. There was no longer anywhere for him to go. His behaviour problems were only manageable in a particular ward."

Discharge

Process

Participants considered that "last minute discharge planning was poor discharge planning."

They spoke about discharge taking place "at the last minute", inadequate notice being given regarding discharge and discharge taking place "too early" without planning or services in place:

"Discharge took half a day to complete. It was very disruptive to my husband who was still distressed. Once home he quickly settled. Having someone stay with him would have been much better for him as a patient."

"The computer failed, resulting in no discharge service, information for the GP or ambos. There was no time for the hospital to talk to the GP."

"A patient was strapped to a barouche from 11.00am to 5.00pm awaiting discharge to his residential aged care facility. He became extremely agitated and needed medical restraint before the ambulance would transport him."

"Waiting two to three hours before the doctor arrived to discharge."

"You have to be in hospital on the right day to connect with the Discharge Planning nurse."

"A 90 year old woman with a fractured arm was sent back to the residential aged care facility after five hours because she was a wanderer."

Those living with dementia could be uprooted from homes. One carer reported that a woman went to hospital due to a fall. Her three daughters organised with the government housing agency to move her from the inner to the outer suburbs "with no consideration for her". Then "she was discharged with no home to go to".

Timing

Participants talked about the confusion and distress caused by “middle of the night” discharges for both community and residential aged care facility patients:

“A woman with Parkinson’s disease, Lewy Body dementia and hallucinations was in Emergency for six hours and never admitted.

She was discharged home to her aging husband from Emergency at midnight. It was difficult for them both to manage this in the middle of the night. Going home at midnight is confusing and distressing for the person with dementia.”

“The patient was discharged ‘home’ on their own, in the middle of the night, without notifying anyone.”

“Mother was discharged too early. Hospital admitted that they don’t want the stress and liability of patients who wander.”

Discharges taking place late in the evening meant that it was “too late to get a service in: not enough notice”.

People were often discharged on a Friday afternoon.

Carers reported the need for them to be “assertive to prevent patients from being discharged too quickly”.

Supported

Examples of positive experiences included:

“We had a helpful experience. The staff were very co-operative.”

“My husband was well looked after at the hospital when he had a fall and he was agitated. He was fine when I arrived and I took him home which was what he wanted.”

Role of Aged Care Facilities

Staff from aged care facilities were concerned at what they perceived to be a “lack of appreciation from acute staff about residential aged care facility care workers”:

“Residents come home to the residential aged care facility very disoriented and take several days to settle back down into their routine and the environment.”

“We hear stories of our residents being shackled to barouches. They can develop pressure areas, adding to the issue they went to hospital for. Hand over on return to the residential aged care facility can be scant if we get one at all. This is a common occurrence, unfortunately.”

One carer spoke about her mother who was discharged with a broken arm “and only Panadol”. The hospital staff said she was safer back in the nursing home as they could not adequately monitor her. She was in great pain. There was no liaison with her GP.

Support Once Discharged

Culturally and Linguistically Diverse

A woman with advanced dementia from a Culturally and Linguistically Diverse background was discharged home with recommendations for the GP to follow up with further monitoring of the health situation and investigation.

However, this woman did not have a GP (except for locum doctors) as she was bed-bound. Dom Care (Domiciliary Care) referred the woman to the community GEM (Geriatric Evaluation and Management) Team, but the geriatrician could not complete the geriatric assessment due to language barriers. Again, the recommendations were for the GP to follow up.

Hence, this woman returned home “with the same old situation: no GP, no further investigation, but completely relying on family and low-level community services (Home and Community Care), whilst her care needs were higher than the High Care Package levels three and four.

Support At Home

Participants supported the principle of people returning to their own homes with support.

However, they observed that the amount of community support was limited. There was a lack of funding for support packages. So it was difficult to get any support for the person living with dementia “to regain or maintain skills and abilities”.

Support from Family

Stories:

“Too much information was provided to the carer upon discharge for them to take in all at once. Allow guidance for a one on one worker to arrange support.”

“The person with dementia refused supports at home. The family had to cope as best they could.”

“It took the patient a while to settle back home, but this was a positive thing. No extra supports were offered. He needed lots of reassurance repeatedly!! He didn’t understand why he had been in hospital. Separation was difficult for the patient.”

Support from Service Providers

Participants expressed their concerns at poor communication and poor involvement with external service providers about discharge:

“As a Care Coordinator for a service provider attempting to support safe discharge, I am sometimes told I cannot have any information due to confidentiality/privacy issues!”

“There are no additional advice or supports information provided should the direct services decline.”

A Respite Service provider indicated that people who used her service came back from a hospital stay having declined significantly and in worse health.

Medication

Participants were concerned at the lack of medication oversight on discharge including inadequate analgesia for pain being provided on discharge.

They observed patients that did not understand what treatment regime they had had in hospital, so were unsure what to do when they went home.

Systems

“We all ask the same questions over and over.”

WHAT NEEDS TO BE DONE?

Commencing the discharge plan process when the person with dementia entered hospital could ensure that timely and appropriate treatment was delivered during the stay and afterwards (AIHW 2013).

Improved communication with family and better coordination with facilities and services can ensure a safe transition with better health outcomes for a person living with dementia.

HIGHLIGHTS

- Communication with family, facilities and services to ensure a safe transition.
- Supports for post-hospital care identified prior to discharge.
- Discussion with family of post-hospital accommodation options.
- Improve discharge processes involving patient and family.

Going 'Home'

So that readmissions would be avoided, participants wanted "discharge to the right place the first time".

Participants sought more appropriate communication between hospitals, residential aged care facilities and families to ensure a safe transition regarding treatment and the care required post-discharge. They did not want "things to happen at the last minute".

The 'hard' conversations regarding discharge plans might include the person with dementia not coping at home and the family feeling guilty about that.

Patients whose condition had deteriorated needed to be assessed to see whether their accommodation was still suitable and appropriate. Families wanted to view all the options rather than just a residential aged care facility as the answer.

Discharge

Process

People with dementia and their carers wanted to be part of the discharge planning process. They wanted this to begin at admission.

They sought a more planned, involved and efficient discharge planning process for a safe and effective

discharge. Documenting previous input would assist future health and discharge planning.

Participants recommended that discharge letters be sent to the GP, the family, the residential aged care facility and community service providers.

Timing

Participants observed that it was best to discharge patients with dementia in the morning back to the residential aged care facility or their home, rather than late in the day or in the middle of the night from the Emergency Department.

Role of Aged Care Facilities

Participants recommended that if there were changes of medication during the hospital stay, that some should be sent to the residential aged care facility, as it took twenty four to forty eight hours to arrange scripts through residential aged care facility pharmacists.

Support Once Discharged

Support At Home

“Are the correct supports in place at home prior to discharge? This is a key question”.

Participants wanted supports identified. They wanted staff to ensure that the patient was going back to a supported environment.

If no supports were available, participants wanted a determination to see if the person with dementia was able to cope at home, to maintain their autonomy, independence and quality of life, particularly if they were on their own.

Issues to consider for at home support included respite, transition care programs, frailty, reduced mobility, convalescence, follow up care, outpatient services, available government allowances, proper pain management and home modification and connection into community supports.

Support from Family

Family members expressed their desire to be involved in the discharge planning decision making. They wanted to be listened to about what happened when the patient with dementia returned home. They recommended family meetings be held before discharge, to get the support of the family and to find supports for the family.

There was concern about whether the carer knew what to do, on the need for carers to be educated on family needs and on their rights as well as the patient's needs and rights.

Participants expressed their concern that too much information was overloading the carers and families. The carers needed support and guidance to make it easier for them to make choices about their own care, as they went about caring for the person with dementia.

Local hospitals needed to have more awareness about local services of support for both the patient with dementia and the carer, in particular respite options.

Service Providers

Participants wanted people to be directed to the right services that could assist them following discharge. This would involve the patient with dementia having an assessment prior to discharge.

Hospitals needed to link to aged care community services. A post discharge follow-up could take place with the residential aged care facility.

People would benefit from having knowledge of carer support organisations.

Participants recommended that church communities be supported to understand dementia and learn how to support people, so they could remain involved in community life.

Support from the GP

Participants wanted better communication and greater liaison by hospital discharge services with family GPs, regardless of whether the person was going back to their home or a residential aged care facility.

Staff Knowledge of Supports

Participants recommended that there be more staff education about services, so that discharge nurses would be more aware of services or a mixture of services for both the person with dementia and the carer.

Systems

Participants sought greater communication between different health institutions when patients were transferred, so that “vital information was passed on”.

REFERENCES

DEMENTIA CARE IN HOSPITALS: COSTS AND STRATEGIES

The report, *Dementia Care in Hospitals; Costs and Strategies*, published by the AIHW in 2013, aimed to “inform service providers and governments on several key aspects of dementia care in the acute setting, so that health funding can be directed to the programs and services that appear to make the biggest difference in improving the experience of hospitalisation for people with dementia”.

The report identified:

- Under-identification of dementia in the community.
- The cost of hospital care for people with dementia, including poorer outcomes and longer stays for the patients and increased costs for the hospital systems.
- Hospitalisation and/or extended stays as a symptom of gaps or discontinuities within the health care system.

The report outlined strategies and practices affecting hospital use including:

1. Strategies outside the hospital for admission prevention strategies.
2. Strategies within emergency departments that aimed to improve identification of dementia and appropriate referral and admission practices.
3. Strategies within the hospital that aimed to reduce the length of stay.
4. Cross-sectoral strategies identifying key strategies that cross between settings, such as end of life strategies.
5. Environmental strategies for improving the physical and social environment where care is delivered.

A multifaceted and integrated approach between hospital, mental health, residential aged care and community services is most likely to ensure that dementia care is delivered in the most appropriate and beneficial setting for the patient.

DEMENTIA CARE IN THE ACUTE HOSPITAL SETTING: ISSUES AND STRATEGIES

In April 2014, a symposium on dementia care in hospitals was hosted by Alzheimer’s Australia. Researchers, policy makers and clinicians talked about the latest research on dementia care and discussed strategies and practical approaches to improve the quality of care.

The report of the symposium, *Dementia Care In The Acute Hospital Setting: Issues And Strategies*, outlined “urgent issues that needed to be addressed”:

- Better identification of cognitive impairment in hospitals.
- Increased training for all staff, including how to communicate with a person with dementia and how to respond to behavioural and psychological symptoms.
- More extensive and systematic involvement of carers as partners in the health care of people with dementia.
- Creation of appropriate physical hospital environments to reduce the confusion and distress of people with dementia.

Sustained commitment and leadership from policy makers, senior management and healthcare professionals is essential if we are to achieve the cultural change that is required to improve the outcomes for people with dementia in the acute hospital setting.

The report identified strategies to improve the outcomes for people with dementia:

1. Identify and manage dementia at hospital admission and plan for discharge from the outset.
2. Involve family carers in the care and support of patients.
3. Train staff to better understand dementia and communicate more effectively with people with dementia.
4. Use alternatives, such as psychosocial interventions, to the use of antipsychotic medication and sedatives.
5. Adapt the hospital physical environment to reduce distractions and help orientate patients with dementia.
6. Reduce avoidable hospital admissions.

TOP 5

TOP 5, developed by the Central Coast Local health District New South Wales, promoted talking with the carer at the start of a hospital admission. It helps to personalise hospital care for patients with memory and thinking problems.

It is a tool to enable staff to work with carers to “tap into the carers’ knowledge and expertise of the person who has become the patient”.

The primary carer’s knowledge of the patient, especially in relation to communication and behaviour, can be the key to assist staff when managing the care of a patient, understanding their needs and providing reassurances in an unfamiliar environment.

The essence of TOP 5 is to:

- Talk to the carer.
- Obtain the information.
- Personalise the care.
- Develop five strategies.

To identify five strategies hospital staff ask carers:

- Are there things/situations that may cause distress eg colours, topics, gender of staff?
- If unsettled, are there words or actions that will help settle and calm, eg listening to music, relocation, reading and lighting?
- Are there set routines that reassure, eg mealtimes, bathing, bedtime?
- Are there any repetitive questions or reoccurring issues that may need specific answers? What is the preferred answer?
- Is there somebody that might be called out for? This could be a person or pet.
- Are there any signs that indicate a need to go to the toilet?

THE DEMENTIA-FRIENDLY SYMBOL

A national dementia-friendly symbol for raising awareness about cognitive impairment has been developed by Alzheimer’s Australia and endorsed by people with dementia.

Alzheimer’s Australia believes that the national implementation of a dementia-friendly symbol would lead to significant benefits for people with dementia and their families.

In its report, *Cognitive Impairment Symbol: Creating Dementia Friendly Organisations*, Alzheimer’s Australia stated that the implementation of the symbol in hospitals “must be conditional on”:

- People with dementia having the right to choose whether they wished to be identified.
- Staff training and education on dementia care and communication.
- Executive level support, as implementation of a symbol would necessitate a review of hospital procedures and policies to ensure the quality of dementia management practices.
- Funding for training and implementation.
- Champions: a select number of staff members who would ensure that a symbol was applied appropriately and who provided further information about the symbol when necessary.

REFERENCES

- Alzheimer's Australia (2013) *Cognitive Impairment Symbol: Creating Dementia Friendly Organisations A Report for Alzheimer's Australia* Paper 32
- Alzheimer's Australia (2014) *Dementia Care In The Acute Hospital Setting: Issues And Strategies*, a report for Alzheimer's Australia, Paper 40.
- Australian Institute of Health and Welfare (2013) *Dementia Care in Hospitals: costs and strategies*. Cat. No. AGE72. Canberra: AIHW.
- Axam A., Hasnip F., Luxford K. (2013) TOP 5 Getting to know You? presentation at Alzheimer's Australia Fifteenth National Conference May 2013, available at fightdementia.org.au/sites/default/files/1100-Axam.pdf.
- Ballarat Health Services (2004) Cognitive Impairment Identifier Project. An All of Hospital Education Program to Improve the Awareness of and Communication with People with Dementia - Linked to a Visual Cognitive Impairment Identifier. Available at www.bhs.org.au/sites/default/files/finder/pdf/final%20report%20DHS%202004.pdf.
- Borbasi S., Jones J., Lockwood C. & Emden C. (2006) Health professionals' perspectives of providing care to people with dementia in the acute setting: towards better practice. *Geriatric Nursing*, 27, 300–308.
- Christie J. & Cunningham C. (2012) *Caring for people with dementia in hospital settings*. Hammond Press: Greenwich.
- Cunningham C. (2006) Understanding challenging behaviour in patients with dementia. *Nursing Standard*, 20, 42–45.
- Draper B., Karmel R., Gibson D., Peut A. & Anderson, P. (2011) The Hospital Dementia Services Project: age differences in hospital stays for older people with and without dementia. *International Psychogeriatrics* 23, 1649–58.
- Fleming R. & Purandare N. (2010) Long-term care for people with dementia: environmental design guidelines. *International Psychogeriatrics*, 22 (7), 1084–1096.
- Foreman P. & Gardner I. (2007) *Evaluation of Education and Staff in Dementia Care and Management in Acute Settings*. Australian Institute for Primary Care. Latrobe University: Victoria.
- Frazier-Rios D. & Zembruski C. (2005) Communication difficulties: assessment and interventions. *Dermatology Nursing*, 17, 319.
- Goodall D. (2006) Environmental changes increase hospital safety for dementia patients. *Holistic Nursing Practice* 20, 80–84.
- Government of South Australia (2012). *South Australian Patient Safety Report 2011-12*. Available at: www.sahealth.sa.gov.au/wps/wcm/connect/b9d947804e387e08bca1bf8ba24f3db9/SAPatientSafetyReport2011-2012.pdf?MOD=AJPERES&CACHEID=b9d947804e387e08bca1bf8ba24f3db9.
- Hanley C. (2004) Delirium in the acute care setting. *MEDSURG Nursing* 13, 217–225.
- Li H., Melnyk B., McCann R., Chatcheydang J., Koulouglioti C., Nichols I., Lee M. & Ghassemi A. (2003) Creating avenues for relative empowerment (CARE): a pilot test of an intervention to improve outcomes of hospitalized elders and family caregivers. *Research in Nursing and Health*, 26, 284–299.
- McCloskey R. (2004) Caring for patients with dementia in an acute care environment. *Geriatric Nursing*, 25, 139–144.
- Older Person Clinical Network (2014) SA Health Services Plan for People with Dementia (and Delirium) 2014–2018 SA Health (final draft)
- Price J.D., Hermans D.G. & Grimley Evans J. (2005) Subjective Barriers to Prevent Wandering of Cognitively Impaired People. *The Cochrane Database of Systematic Reviews*. CD001932.
- Pritchard E. & Dewing J. (2001) Older people with dementia in acute settings. *Nursing Older People* 12, 21.
- Sampson E., Blanchard M., Jones L., Tookman A. & King M. (2009) Dementia in the acute hospital: prospective cohort study of prevalence and mortality. *The British Journal of Psychiatry*, 196. 61–66.
- Travers C., Byrne G., Pachana N., Klein K. & Gray L. (2013) A prospective observational study of dementia and delirium in the acute hospital. *Internal Medicine Journal*, 43(3). 262–269.

ALZHEIMER'S AUSTRALIA SA

Alzheimer's Australia SA is the charity for people living with dementia and their families and carers.

Alzheimer's Australia SA leads the way in providing support, empowerment and advocacy for people impacted by dementia.

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