

**Top 5 - A win-win partnership for carers & staff in an acute hospital setting.**  
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**Abstract**

Top 5 is a practice innovation developed in acute-care hospital setting to meet the unique needs of inpatients with confusion. The process is simple and engages carers as active contributors to person-centred care for individuals with disabling conditions such as dementia, stroke, Parkinson's disease, sensory impairment and communication difficulties.

Data sourced from carer stories showed carers were frustrated with healthcare experiences as their knowledge of the unique needs of the person they care for was often overlooked or discounted by staff. Many carers advised when their expertise was sought it was not effectively communicated to others. Staff reported difficulties in managing unsettled behaviours of confused patients and were keen to avoid the risk of adverse outcomes. Carer understanding of the person, their behaviours and patterns of communication was seen as pivotal information for health professionals.

A pilot project engaging carers as partners in health, demonstrated significant improvement in the experiences of patients, carers and staff. Patients were noted to have a "quicker recovery", had "less agitation, frustration and distress", "more effective communication", and "increased ability to relate". Staff reported a positive increase in their comfort and confidence in working and communication with inpatients with confusion. Carers reported that staff appeared to have an increased awareness of their role as carer (59% to 93%), and sought and acknowledged their advice (53% to 77%).

Rolling Top 5 out as a practice improvement strategy in the acute care setting has been met with both support and resistance. Although staff recognise it as a worthwhile initiative, the challenge of ownership in a busy ward has required support from ward leaders, and a designated worker to promote a Top 5 presence. The Top 5 worker has had the role of developing resources, training staff, communicating with carers and carer groups, and refining the initiative.

*Top 5 is a carer and staff partnership initiative, to personalize care, in an acute hospital setting, for patients who are cognitively impaired. This paper aims to identify and discuss the implementation processes, challenges and successes. (Priority Action #1, #3, and #4, NSW Carers Action Plan 2007 - 2012)*

## Identifying a common need

The NSCCHAS (Central Coast Sector) Working Party for Patients with Confusion was looking to achieve a paradigmatic shift from a focus on management of challenging behaviours, to develop a more person-centred approach through an understanding of what is being communicated by the behaviour. Staff wanted to be able to provide personalised care in a calm and effective manner for the patient who is cognitively impaired, and in a safe environment for all patients and staff.

Meanwhile, the Carer Support Unit (CSU) consultations with carers of people with a cognitive impairment, consistently highlighted that carers knew what triggers could cause distress to and/or aggression in the patient they care for; that carers understood the gestures made to communicate needs, and could settle and calm a patient more quickly and effectively than staff by using the 'right' words or actions. Carers were worried that staff would not know how to approach and respond to their care recipient. They wanted to share this key information with all the staff who interact with the patient, for the benefit of everyone, and the well-being of the patient.

Both groups desired patient-centred care, but needed a mechanism to achieve it. From this objective Top 5 was developed to connect the two parties to share information and negotiate strategies that could be implemented by staff on the ward. This communication was aimed to promote a calm and responsive environment for the patient with a cognitive impairment.

In a nutshell Top 5 was as follows: If an inpatient has a cognitive impairment, a staff member speaks with the primary carer to identify the 5 best strategies they think staff could use to support the patient. These strategies would assist in communicating patient's needs, and in keeping them reassured and secure. Staff wrote these onto a Top 5 Strategies form which was placed in the bed chart notes. To ensure personalized patient care and management, a discreet identifying label was placed on the top of the bed head so that all staff became aware of the existence of the 'Top 5' strategies.

## Pilot Project

In 2007, a pilot project was undertaken, to trial and evaluate 'Top 5' across five acute 'Rehab and Aged Care' wards in two Central Coast public hospitals. Evaluation of pre and post Top 5 initiative, demonstrated significant qualitative and quantitative improvement in the experience of all parties. Patients were noted to have a "*quicker recovery*", their behaviour demonstrated "*less agitation, frustration and distress*" and they could "*communicate more effectively*" and had an "*increased ability to relate*". Staff reported a positive increase in their comfort and confidence in working and communicating with inpatients with confusion. Carers reported that staff appeared to have an increased awareness of their role as a primary carer (59% to 93%), and that their advice was sought and acknowledged (53% to 77%). Keane S. "*Top 5 – Engaging Carers in Person Centred Care for People with Confusion and / or Communication Difficulties.*" Paper presented at the 'Getting on with Life – Rehabilitation and Chronic Illness in Old Age' Conference, AAG, Wollongong, April 2008.

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Eight months after the trial, wards that were previously involved in the pilot were invited to discuss their experience of 'Top 5' since the trial, and offer suggestions for improvement. **Although Top 5 had been shown to be successful, most wards had seen it as a pilot and in the absence of CSU involvement no longer implemented Top 5.** Some lost impetus because of changes within ward leadership, loss of key workers, and new staff being unaware of the initiative.

## Development of Top 5

Following the pilot's demonstrated success of Top 5, funding was granted for a project worker to implement Top 5 across all Central Coast acute hospital wards. Consultations were held with ward leaders. The following issues were identified:

- The system of identifying patients with a Top 5 "doesn't work"  
*"The bed board sticker eventually lost its significance. Staff being busy did not have time to go and move the sticker every time the patient was moved to another room – an average of 3.4 times per admission on a surgical ward. Sometimes the sticker was just left on the bed board, even when a new patient was in the room."*
- Top 5 is too time consuming  
*"When nurses talked with carers to elicit the Top 5, they found it too time consuming. They got too much information and had no time to sift the wheat from the chaff".*
- Staff turnover leads to loss of knowledge of Top 5  
*"teach staff a method of interacting with the carer. Develop a list of key questions and prompts."*

To address the above issues, a new "Top 5" logo, and resources were developed. Protocol changed to have a Top 5 ID tag placed at the front of the Bed Chart notes. This raises awareness of staff to the existence of Top 5 strategies within the Bed Chart notes. As the Bed Chart is always with the patient, even when transported for tests, Top 5 strategies could be used by allied health staff to distract or keep the patient calm e.g. during scans, x-rays, etc.

A small Top 5 sticker was used to alert all ward staff to patients who have a 'Top 5'. The sticker is placed on the spine of the Medical Record, and also within the medical record, noting that the carer has identified strategies for Top 5.

A new Top 5 pamphlet emphasises that strategy suggestions need to be negotiated with staff to ensure they can be implemented within the ward environment. The pamphlet includes questions to help carers consider what they know, and do at home, that is effective in maintaining a calm environment. This assists carers, when approached by a staff member, in quickly identifying the best Top 5 strategies for the ward. Staff members can also use the questions to direct the carer conversation to achievable strategies.

Nursing inservices to introduce the Top 5 initiative are held in each ward. Resources are provided, including a folder explaining the concept, the role of the primary carer, the Top 5 process, examples of strategies, posters, pamphlets, ID tags, strategy forms, tips for talking with carers, and considerations when interacting with cognitively impaired patients.

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It was hoped that staff would be enthusiastic in approaching carers after they came to experience the improvement in management of a confused patient, after Top 5 strategies are identified and implemented. This seems to have happened in some wards.

*"At the inservice, I just thought 'here is yet another thing we have to do', but after that last shift with Mr.... (cognitively impaired patient who had been very disruptive and aggressive prior to Top 5)... I LOVE TOP 5." Nurse on Surgical Ward.*

It was assumed by staff that patients who were from a Residential Aged Care Facility (RACF) were not considered 'Top 5' candidates, as they did not have a primary carer. Subsequently education around the role of carers was expanded to include those who maintained their caring role throughout their care recipient's time in an RACF. The process of Top 5 was also expanded to include 'Key Workers' as appropriate sources of patient information and management strategies, particularly if there was no carer. A Key Worker is a paid worker who has a caring role and knows the patient really well. Key workers could be from community services or RACFs. To clarify who would be appropriate for Top 5, an Algorithm was developed. (See slide).

*"Does she have her cardigan with the fur collar – she loves it. If not, could you give her a heated blanket as she gets quite cold. She has a very very quiet voice – you may think she is just mouthing, but if you get down very close to her, you will hear her voice. When she fidgets and points to the door, she wants to go to the toilet. Please don't have a male nurse bath or toilet her...she is a very modest lady" Key Worker from Nursing Home*

Reintroducing Top 5 has relied on active support from at least one ward leader such as the NUM, Clinical Co-ordinator, or the CNE. At in-services, most nurses agree that it is a 'good idea', and that it would be very useful when they have an agitated and confused patient. But when told it would be best implemented by nursing staff, the common reply is that they are already too busy and do not want to have another thing to do. After positive experiences, staff come to understand that spending some time getting the Top 5 strategies from the carer, is well worth it, compared to the large amount of time saved in patient management and care.

*"My mother was a paediatric nurse in Scotland during World War II. She thinks the nurses are too busy, so she won't use the buzzer during the day. At night she will not use the buzzer as she believes the nurses are sleeping. Mum is not incontinent, but does need someone to take her to the toilet. At night my brother sets the alarm for 1am, wakes mum, and takes her to the toilet - she has never wet the bed. When my brother or I visit mum in hospital we always take her to the toilet. If a nurse took her to the toilet regularly, and woke her up at night to toilet her, she wouldn't be incontinent, and it would be more dignified for mum. It would save the nurses a lot of work in cleaning mum, and making the bed." Carer*

The issue of who is responsibility for initiating Top 5 is approached differently in each ward. Some nominated a specific person to 'do the Top 5'. Others nominated a specific 'role' e.g. all AINs, or an EN who is a 'floater'. Some wards ignored it, hoping that the 'project worker' would continue to 'model' implementing Top 5, and others used the NUM or Clinical Co-ordinator to request/remind the nurse assigned to a specific patient to initiate a 'Top 5' with the carer.

Some wards use cues to remind staff e.g. adding a Top 5 column in their handover sheet; noting Top 5 on the white board next to the patient names, regular Top 5 quotes in their 'ward newsletter', posters in the treatment room, posters in the 'tea room', posters at the nurses' station. Carers are also targeted by pamphlets and

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posters placed at the ward reception desk, at the entrance to the ward, the patient lounge room, and on walls outside patient bedrooms.

On surgical wards the implementation of Top 5 with a confused patient, has shown to **identify patients who were suffering a Delirium**. When the medical history reveals the patient has a dementia, confused behaviour is often seen as 'normal'. However when staff talk with a carer to identify the Top 5 strategies, the carer has the opportunity to describe normal behaviour and to identify current behaviour as 'atypical'.

*"That is not my Dad! Two days ago he was driving me to the shops!  
He is a bit forgetful and can't manage some things, but he can discuss current events.  
He has a good sense of humour, and is always polite. He is a true gentleman." Carer.*

Surgical wards have also reported that when patients have a Top 5 the staff are more successful in settling them, decreasing their attempts to move around the ward, reducing the potential for falls.

A new position of **CNC Dementia/Delirium** for the Central Coast sector, was created and filled earlier this year. The CNC has enthusiastically embraced Top 5 and encourages nursing staff to initiate Top 5 with carers, and to implement strategies. This synergistic relationship has accelerated the rollout of Top 5 across the hospitals. In less than twelve months Top 5 has been accepted in 14 wards.

Top 5 is also being used in our **Pre-admission Clinics**, and in the **Integrated Booking Units**. If a patient with cognitive impairment is having planned surgery, a Top 5 Pamphlet is given to the carer. On admission of the patient, the carer is encouraged to bring in a prepared list of strategies to support communication and care, that can be discussed and negotiated with staff.

### **ASET**

At the Gosford and Wyong Hospital, the ASET team are aware of the Top 5 initiative. The ASET nurse is in a unique position to record an extensive personal history of the patient via the carer, and when possible will initiate a Top 5.

As the ASET nurse is unaware as to which ward the patient will be sent, they contact CSU to follow up the patient in the ward. This is to ensure staff are aware of the 'Top 5' initiated and to encourage dialogue with the carer. It is still imperative that the ward staff approach the carer, or key worker, to achieve agreement of the best 5 strategies that are appropriate to that ward.

### **Dementia Carer Groups**

Consultations were held with community based dementia carer groups to invite comments and suggestions for the Top 5 initiative. Carers immediately recognised the benefits for their care recipient, and were very keen for Top 5 to succeed. Some carers suggested that they could prepare for hospital by pre-writing the strategies, so that they could give them to the ward staff upon admission of their care recipient. The major concern from carers was whether the staff would implement the strategies suggested. It was emphasized that strategies must to be discussed and **negotiated with ward staff** to ensure that they are 'do-

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able' within the ward. Carers were reminded that this process also promotes valuable dialogue between staff and carers that may help in identifying 'atypical' behaviour, signalling a medical problem e.g delirium.

Carers were also enthusiastic about including Top 5 into the admission process for Residential Aged Care Facilities (RACF). Some carers, who have their care recipient living in a RACF, asked if they could show the resources to the RACF management, as they believed it would be beneficial to residents and staff.

### **Residential Aged Care Facilities**

To date two aged care facilities have integrated Top 5 into their ward protocol. One facility has two low care units totalling 75 beds, and another low care unit that is dementia specific has 15 beds. Over the next few months they are planning to implement Top 5 into their High Care unit of 72 beds. This facility is placed within the Hunter New England Region. (Slide)

The other facility has 40 low care and 20 high care beds. This facility is located within the Wyong municipality. It is part of Uniting Care, Hunter region, who are currently discussing the inclusion of Top 5 across all their Aged Care Facilities, and to also embed it within their **Community Outreach programs**. (Slide)

### **Sustainability**

As the Top 5 initiative picks up momentum across the sector, more staff are becoming aware of the benefits of having strategies in place to support communication with, and care for patients with cognitive impairment. Carers' increased awareness of the 'Top 5' initiative through support groups, pre-admission clinics, or previous hospital admissions, creates an expectation of 'Top 5' being implemented for their care recipient whilst in hospital.

Expanding Top 5 into RACFs on the Central Coast, will mean that eventually most patients from Low and High Care beds will be sent to hospital with the Top 5 Strategies Form completed.

Continuing education is a must to ensure the ongoing success of the Top 5 initiative. This will be achieved through staff in-services; yearly mandatory training, and ward orientation programs for new staff.

### **Transferability**

Top 5 is currently being implemented within 4 area health regions.

GSAHS, and NCAHS have requested information on the 'Top 5' initiative through their Dementia/Delirium CNCs. Discussions within their Aged Care teams about 'Top 5' have lead to a commitment to implement the initiative. Templates for all resources – brochure, strategies form, labels, tags, staff training material, and posters – have been supplied to them to support the process.

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'Top 5' has been adopted and adapted by Carunya Dementia Day Therapy Centre and Carer Support Service, SESIAHS. Appropriately, they have modified the pamphlet to suit their service. (Slide)

## **CONCLUSION**

'Top 5' helps to personalise hospital care for patients with memory and thinking problems. It is a simple concept of asking for information and recording it. The information from the carer, who has expert knowledge of the individual, is distilled into ward based strategies to improve patient communication, and to support care. These strategies are recorded and are accessible to all ward staff.

On presentation of the Top 5 initiative both staff and carers are quick to see the advantages of having strategies available to improve communication and care.

### **Staff recognise the 'win' of**

- having a safer and more settled environment to work in,
- increased confidence in communicating with a cognitively impaired patient
- feeling empowered to provide more effective care

*"I was so nervous when I was told I would be looking after Mrs...(a patient with end stage dementia from a nursing home) as I just didn't know how to approach her. But when I saw the Top 5 strategies I was so grateful to know that I could make her comfortable, and I could really care for her as an individual."* New Graduate Nurse.

*"Having a Top 5 for Mrs...(a patient with end stage dementia) and reading about what she likes, and dislikes, reminded me that she was an individual ... it gave me a real sense of who she is."* Experience RN of 20 years

### **Carers recognise the 'win' of**

- feeling more confident in the health care provided
- knowing their care recipient will be more settled and comfortable when they are not at the bedside

*"Staff should know if my wife starts to mumble and talk to herself she is becoming anxious – a calm reassurance like 'It's okay Beryl, you are safe, we are looking after you' is all she needs".* Carer and husband.

- feeling respected and valued with regard to their knowledge of the patient

*"Even though Dad hasn't driven for 12 years, around 4pm every day Dad starts to look for his car keys. He always put the car in the garage around 4pm. You just have to tell him the car is already in the garage, and he will settle down."* Carer

Due to the nature of the health care environment, the Top 5 initiative must be flexible to accommodate a variety of clinical situations. Top 5 is ongoing action research in practice. With every step Top 5 has developed and changed, but the fundamental structure is fixed, and strongly reflects the values that all Carer Support Units across the state hold:

**"Carers are Recognised, Respected and Valued"**

**"Carers are Partners in Care"**