Engaging with carers to improve the care of individuals with dementia

**Project Overview**

The principles of the TOP 5 initiative are illustrated below:

- **TOP 5**
  - Talk to the Carer
  - Obtain the Information
  - Personalise the Care
  - 5 strategies developed

TOP 5 promotes the inclusion of carers as part of the healthcare team and acknowledges the value of carer information for people who have memory problems (such as dementia). TOP 5 encourages staff members to engage with carers and understand their five most important carer tips when caring for their loved one, which supports personalised care.

**Project Background and Objectives**

TOP 5 was initially implemented in 21 hospitals across the state (both public and private), with successful outcomes. The Clinical Excellence Commission's research project is now investigating the use and impact of TOP 5 in 'red flag' linkages between hospital services (primarily emergency departments and pre-admission clinics), Residential Aged Care Facilities (RACFs), community services, and Ambulance Services NSW, over a period of 12 months.

**Top 5 Carer Brochures**

**Engaging with Carers**

Staff members at participating sites will approach carers to develop the TOP 5 strategies.

- **Hospitals** | Carers are engaged at the time of the patient's admission, either in ED or pre-admission/peri-op clinic.
- **RACF** | Carers may be engaged at the time of the resident's admission, or, for longer term residents, at carer conferences/meetings with staff.
- **Community** | Staff members who visit clients in their own home will approach the carer who is living with the client or may contact the carer or NOC via phone.

The TOP 5 strategies are written on a yellow standardised form.

**How to Write an Effective TOP 5**

A TOP 5 strategy needs to give the 'why'.

- Follow this statement with the personal preference for care and what the outcome will be if the strategy is/is not followed.

**Example**

**Why** | “Mary is very modest”

**Strategy** | “Please ensure that Mary’s personal hygiene is carried out by a female attendant.”

**Outcome** | “Mary will become very distressed if a male bathes or toilets her”

**Actions Taken**

**Site Selection** | Ten hospitals and associated RACFs, community services and NSW Ambulance.

**Governance** | A TOP 5 Steering Committee as well as local implementation teams at each site.

**Education and Implementation** | TOP 5 education to staff at all sites was provided.

**Development of a Toolkit** | A TOP 5 paper-based toolkit suited to different health service was developed.

**Communication** | Monthly teleconferences are held and a bi-monthly newsletter produced.

**Mid-Way Site Visits** | Mid-way site visits were conducted at each site in March – April 2015.

**Outcomes**

**Carer Feedback** | Carers believe their loved one has benefited as a result of the TOPS initiative.

**Staff Feedback** | Staff members recognise the value and importance of the program.

**Top 5 is a good idea and I appreciate the fact that TOP 5 helps my husband settle in whilst admitted in hospital.**

**Staff are always very grateful as I think it helps them to feel that their relative is not just a patient but an individual and we are trying to address their individual needs to make their transition from their home environment to hospital less stressful or traumatic.**

**Successful Top 5 Strategies**

Staff from a number of study sites have provided the CEC with their successful TOP 5 strategies that they have implemented for the individuals they care for.

**Example 1 | Referring Hospital**

Bob used to manage a delivery yard and part of his job was to get the trucks on the road by 4:30am each day. If Bob becomes agitated around this time just say ‘Bob the trucks are all gone’ and he will settle.

**Example 2 | Dementia Day Care Centre**

A gentleman with dementia who likes to be of assistance became quite agitated and wanted to leave the day centre. The strategy was to ask him to help with some tasks around the centre. The gentleman then became pre-occupied with the task and settled down.

**Example 3 | Community Service**

A client with dementia lives alone with her cat and worries about going to hospital. The contact name of a friend who can look after the cat is/is not followed.

**Overcome Barriers**

- Focusing on what the carer would like to happen to make the patient feel comfortable in hospital.
- Providing carers with contact details for follow up.
- Developing a staff schedule.
- Improving communication between wards and encouraging feedback during transfer of care.
- Promoting further TOP 5 awareness to all staff.
- Promoting TOP 5 as a team approach.

**CCLHD Acknowledgement**

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