

TOP 5 Toolkit



Hospital

Integrating carer knowledge to improve care for patients
with dementia

Introduction

A recent report from the World Health Organization (2012), '*Dementia – A Public Health Priority*' shows that the estimated prevalence of dementia for persons aged 60 and over ranks Australasia as the fourth highest in the world after Latin America, the Caribbean and Western Europe. The number of people globally who are living with dementia in 2014 is estimated to be 35.6 million and by the year 2050 this global figure is expected to reach 115.4 million.

Between now and 2050, the number of Australians aged 65 to 84 years is expected to more than double and the number of people 85 years and over more than quadruple. With an ageing population, increasing levels of dementia and other ageing-related diseases will lead to increasing pressures in the health care system. To improve the care of patients with mental health conditions, new approaches are required recognising the benefits of empowering patients, family and carers.

Dementia is third leading cause of death after heart disease and stroke. With 26,000 new cases diagnosed annually in NSW, it is estimated that by 2033 the total number of cases in NSW will be 341,000. (NSW Health Guideline – GL2011_004 - Dementia Services Framework 2010-2015).

Patients, families and carers are increasingly being recognised as important members of the health care team. Often carers have valuable information about patients that could aid health care professionals. With the introduction of the National Safety and Quality Health Service Standards, (Australian Commission on Safety and Quality in Healthcare 2011) now more than ever, there is a need to actively engage with consumers to provide a health service that remains responsive to patient, carer and consumer needs. The promotion of increased patient, family and carer engagement supports the NSW Health's CORE values.

The *Partnering with Patients* program of the Clinical Excellence Commission (CEC) aims to work with NSW health care services to improve the quality of care by responding to the needs and preferences of patients while equally engaging staff in creating supporting environments for all (<http://www.cec.health.nsw.gov.au/programs/partnering-with-patients>).

TOP 5

The TOP 5 initiative was conceived and piloted in hospitals in the Central Coast Local Health District (CCLHD) and is used for all patients with cognitive impairment. Following the successful outcomes of the initiative in CCLHD, the Clinical Excellence Commission (CEC) was granted funding from the HCF Medical and Health Research Foundation to assist in the further uptake of the initiative focusing on personalising care for patients with dementia who are hospitalised.

For Phase 1 of this initiative, TOP 5 was applied as an approach to gaining carer information to personalise care for patients with dementia when requiring hospitalisation.

TOP 5 is:



- **Talk to the Carer:** Encourages staff to talk to the carers of individuals with cognitive impairment. For individuals who are removed from their usual place of residence and are experiencing pain or discomfort, anxiety levels are often high. It may not be easy for staff to communicate effectively or understand the often subtle signs that may indicate that a person's anxiety is escalating. This causes frustration for staff, distress for the carers and of course the individual with dementia.
- **Obtain the Information:** It is possible to gain real insight into the individual with dementia from a carer and by engaging and gently prompting the carer, staff can obtain cues and tips to understand how the patient communicates and reacts when their routine changes or if they are in a strange environment.
- **Personalise the Care:** The care can be personalised using agreed strategies in caring for the individuals to lessen anxiety, distress and provide a safer environment. The carer expertise and knowledge is acknowledged. The staff and carer work as a team to develop actionable strategies to assist in the care of the individual.
- **5 Strategies Developed:** Five strategies are developed after consultation between staff and the carer to ensure that the strategies are workable in the setting where the individual is cared for. The agreed strategies are recorded on an identifiable TOP 5 form, can be included in the individual's care plan, and kept in a place that enables all staff to access this information to support the care provided. Up to five strategies may be recorded, however, in some cases there may be only one or two relevant strategies.

The TOP 5 initiative was implemented as one approach to lessen anxiety, confusion and disorientation for the patient and to acknowledge the value of the carers knowledge in achieving this. Overall analysis of the CEC program indicated that that the use of a low cost, communication-based strategy for patient care is associated with improvements in patient outcomes, safety, carer experience and staff satisfaction whilst additionally providing potential cost savings to health services.

The CEC has attained a second grant from the HCF Research Foundation to investigate the use of TOP 5 in 'referral' linkages between hospital services (primarily emergency department and pre-admission clinic), Residential Aged Care Facilities (RACFs), NSW Ambulance services and community services for a period of 12 months. Hospitals in the initial study indicated that transition of TOP 5 information between the hospital and these linkages would be beneficial for people with dementia.

Identifying the need

With the prevalence of dementia expected to increase substantially in the coming years, dementia is identified as a National Health Priority within the recent changes to Aged Care Health Reform. There is increasing evidence that patient based care is integral to the management of patients with dementia and other cognitive impairments. The promotion of personalised care planning has provided positive outcomes. The end result has benefits for patients, carers and staff and provides a safer environment for all concerned.

Person centred care has been shown to be linked with improved safety:

- Decreased mortality (Meterko M et al (2010) Health Services Research)
- Decreased rates of hospital-acquired infection (DiGioia A M et al (2008) Agency for Health Care Research and Quality)
- Decreased surgical complications (Murff et al (2006) Qual Saf Health Care)
- Higher quality clinical care/best practice (Jha A et al (2008) New England Journal of Medicine)
- Improved patient functional status (DiGioia A M et al (2008) Agency for Health Care Research and Quality)

The CEC's *Patient Based Care Challenge* promotes encouraging staff to view patients, family and carers as care team members.

The National Safety and Quality Health Service Standards (NSQHS Standards) developed by the Australian Commission on Safety and Quality in Healthcare include Standard 2 "Partnering with Consumers" which provides the framework for active partnerships with consumers by health service organisations. The standard includes evidence about significant benefits from such partnerships, including clinical quality and outcomes, the experience of care and business and operational benefits.

Evidence shows that everyone can benefit from partnering with consumers. TOP 5 clearly demonstrates such a partnership approach to care. Whilst the first phase of the evaluation showed that TOP 5 is simple and easy to use, it is important for sites to put in place a local team

to support introducing a sustainable approach to TOP 5.

The role of local leadership

At each hospital, governance should be established to link in with existing approaches to improving quality care. Minimally, your local implementation team should include:

- Executive sponsor – ideally the General Manager, Director of Nursing or designee
- Clinical Champion in each area where TOP 5 is implemented – a senior clinician who can champion the TOP 5 initiative and help engage local clinical staff (i.e. Emergency Department, Pre-Admission clinic and ward area)
- Local Site Liaison – a committed and enthused individual who will act as the a focal contact point for the lead site implementation team

Local implementation

Educational tools to introduce staff to the process and how TOP 5 will work in your site are provided in this toolkit (see Appendix for resources). It is acknowledged that local implementation will vary at each site with a need to adapt to local resources and different levels of service provision.

Your local site will need to form an implementation team to progress the implementation (as suggested above). Local staff will need to ensure education is ongoing so all staff involved in this initiative will have the knowledge to participate effectively.

How will TOP 5 work in your facility?

Staff members at your hospital from the emergency department or the pre-admission clinic may come across a patient with dementia who has an existing TOP 5 strategy form in place (see Appendix B). This TOP 5 strategy form (see Appendix E) can be placed in the patients clinical notes, so that it is clearly visible to all healthcare staff. The TOP 5 strategies can be reviewed by staff and may require minor amendments to adjust for the clinical setting and that patient's current condition.

Alternatively if a patient with dementia arrives at your hospital without a TOP 5 in place, an Aged care Services Emergency Team (ASET) nurse, aged care nurse (or other suitable staff member) may initiate a TOP 5 with the patient and carer. This process can be initiated in any ward or department in the hospital.

Once the TOP 5 strategies are received a TOP 5 tag (see Appendix G) can be placed on the top of the bedside notes or clinical notes, so that all staff that interacts with the patient will be aware that within the notes, strategies to support care of and communication with that patient, are available.

A TOP 5 sticker (see Appendix H) can be placed in the patient's care plan, that identifies a TOP 5 entry, that documents: "This patient has a TOP 5 strategy in their notes to assist with patient care."

This TOP 5 form can be used by each care provider who cares for the patient and should travel with the patient once they are discharged (either to another ward, hospital, to their home, or to a residential aged care facility). If the patient is transferred home or to a residential aged care facility,

via an ambulance, a copy of the TOP 5 strategies should be handed over to the paramedic or patient transport officer, who in turn will pass it on the staff at the receiving facility. Ambulance staff may also utilise the TOP 5 strategies whilst the resident is in their care.

Review of the process

It is important that each time TOP 5 is introduced into the care of a patient, it is considered an opportunity to learn and improve the experience of care provision. A local review process should be conducted on a regular basis and the information obtained shared with the local team members. The identification of any barriers to implementation should be discussed locally to determine solutions. The capture of positive feedback from carers and staff can also be shared with the local team and management to demonstrate the benefits of the initiative. It will be important for the local leaders to maintain support and encouragement to the staff involved to ensure that the initiative is sustainable and becomes part of local policy and practice.

How to evaluate the effectiveness of TOP 5?

An evaluation on the TOP 5 program may be conducted locally if desired. Suggestions of evaluation measures are: processes, clinical impact, carer and staff experience and acceptability.

Evaluation components could include:

- Clinical and operational benefit measured by changes to the numbers of falls, use of restraint and incidence of aggressive behaviour (pre and post implementation)
- Impact on dementia/behaviour assessments
- Impact on carer experience through surveys
- Survey of staff experience and awareness of the initiative
- Cost implications through local site liaison surveys

Examples of staff and carer surveys have been provided in Appendix O – R.

If your site opts to include an evaluation methodology for the TOP 5 program, it is useful if this is outlined to staff in Appendix H and K.

RESOURCES

Appendix A – TOP 5 Guiding Principles

Appendix B – TOP 5 Process for hospitals

Appendix C –TOP 5 Brochure for hospitals

Appendix D – TOP 5 Poster for use in the facility

Appendix E – TOP 5 Strategy Form

Appendix F – TOP 5 Tag Process and ID Tags

Appendix G – TOP 5 Sticker for patient's medical notes [to be printed on Avery L7156]

Appendix H – TOP 5 Information Sheet for Staff

Appendix I – TOP 5 How to Write Effective Strategies

Appendix J - TOP 5 Training Tool for Staff (Scripts)

Appendix K – TOP 5 Educational Slides for staff

Appendix L – TOP 5 Education Posters

Appendix M – TOP 5 Carer Posters for use in your facility

Appendix N – TOP 5 Lanyards for staff

EVALUATION TOOLS:

Appendix O – TOP 5 Pre-implementation staff survey form for emergency department staff

Appendix P – TOP 5 Post-implementation staff survey form for emergency department staff

Appendix Q – TOP 5 Carer Information and Consent Form

Appendix R – TOP 5 Carer Survey Form



TOP 5 GUIDING PRINCIPLES

Partnership

The integration of carer knowledge will provide a person centred approach to the care of patients with dementia. TOP 5 will embody the principles of partnership and recognise carers as a key member of the care team. This will be evidenced by:

1. Informing carers of patients with dementia of the concept of TOP 5
2. Informing carers of the value of their knowledge and engaging with carers to assist in the communication of this information
3. Facilitating carers to directly engage with staff to develop TOP 5 strategies

Responsive

4. Staff are educated about the benefits of the TOP 5 initiative
5. Staff are empowered to engage carers to integrate carer knowledge
6. Staff are provided with the expertise to prompt the dialogue with carers
7. TOP 5 strategies are developed in partnership with carers to personalise the care

Caring for all

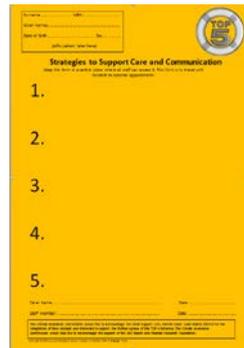
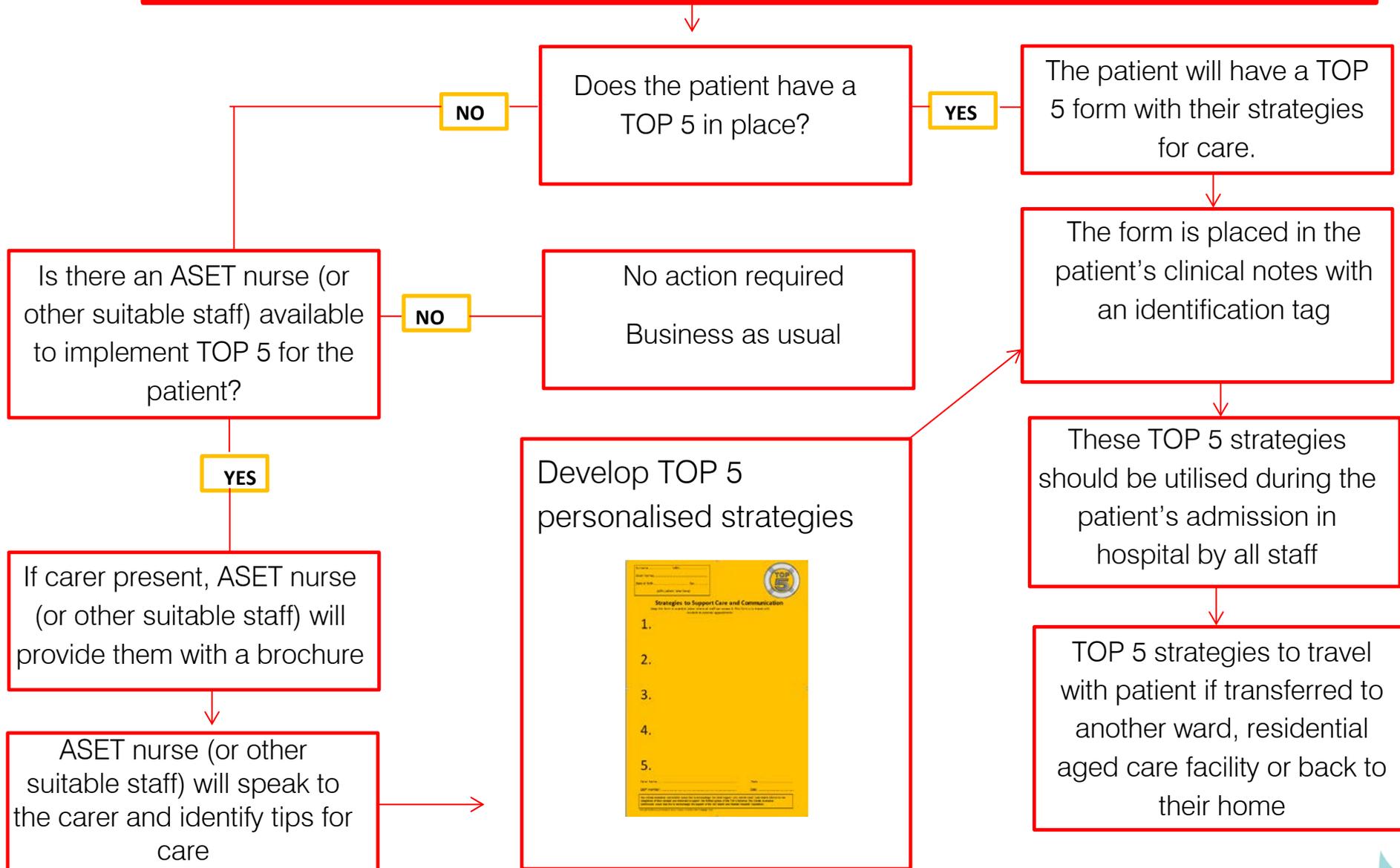
8. TOP 5 is one way to integrate carer knowledge into personalised care of a person with dementia. The intent is to lessen anxiety and de-escalate inappropriate behaviour thus providing a safer environment for staff and for patients who have cognitive difficulties.
9. Every time TOP 5 is initiated it should be seen as an opportunity to improve the quality of care and communication to benefit patients, carers and staff.

The Clinical Excellence Commission would like to acknowledge the Carer Support Unit, Central Coast Local Health District for the integration of their concept and materials to support the further uptake of the TOP 5 initiative. The Clinical Excellence Commission would also like to acknowledge the support of the HCF Health



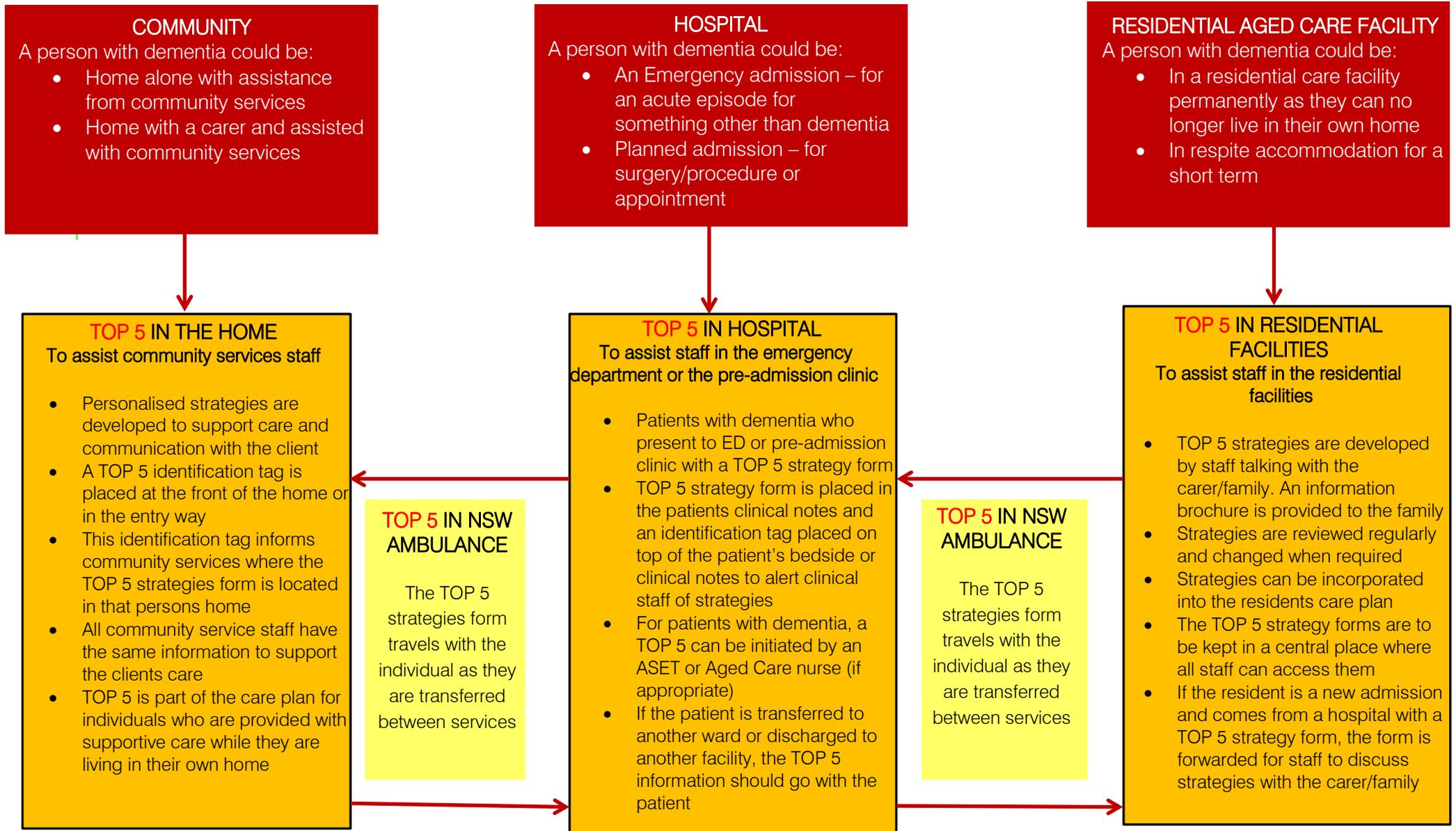
TOP 5 PROCESS – HOSPITALS

Patient with dementia presenting to Emergency Department, Pre-admission clinic or ward in hospital





TOP 5 PROCESS ACROSS HOSPITALS, RESIDENTIAL AGED CARE FACILITIES AND COMMUNITY SERVICES





Who is a carer?

A 'carer' is a family member, a friend or a neighbour who provides support to another person who is frail, aged, disabled or chronically ill.

They do this in a regular, sustained manner without payment apart from a pension or carers benefit.

Carers can be of any age from diverse cultural and linguistic backgrounds.

A primary carer is the person who takes most responsibility for providing care for the person requiring support.

What does a carer do?

Some carers assist with activities of daily living such as feeding, bathing, dressing, toileting, or administering medication.

Carers may also help with social support, transport, medical appointments, decision making and emotional support.

Thank you for sharing your information with us.



We are using TOP 5 to help us improve the personalised care of the patient.

For more information contact:

Local Facility/District Contact Details



Facility Logo

The Clinical Excellence Commission would like to acknowledge the **Carer Support Unit, Central Coast Local Health District** for the integration of their concept and materials to support the further uptake of the TOP 5 initiative. The Clinical Excellence Commission would also like to acknowledge the support of the **HCF Health and Medical Research Foundation**.

Clinical Excellence Commission - TOP 5 Phase 2 - June 2014



Carer TOP 5 Information

HOSPITAL



TOP 5 helps to personalise care for patients with memory and thinking problems

Identifying TOP 5 strategies

The following questions are about the person that you care for and will assist us in personalising the care.

- **Are there things/situations that may cause distress?** e.g. colours, topics, the gender of staff.
- **If unsettled, are there words or actions that will help settle and calm?** e.g. listening to music, relocation, reading and lighting.
- **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 signs that indicate a need or a want?** e.g. fidgeting to indicate a need to go to the toilet.

Carers say: "It is important that staff tell Dad that his meal has arrived and they hope he enjoys it – if they just leave the tray he will not recognise it as his."
Brad – carer for father

What will happen?

A member of staff from the service will speak with you when the patient is admitted to hospital. The patient will have been identified as having memory or thinking problems.

A member of staff will talk with you about TOP 5 and explain how it can help with the care of the patient. They will ask you about the five most important things staff should know to communicate with and reassure the patient.



This information is called

This information (also referred to as strategies) will be included in the patient's notes to allow all staff involved in care to access this information to support and promote optimal care.

Staff said: "Bob used to get agitated every morning at 4.30am. A friend came to visit and said Bob used to manage a lorry yard. The Lorries needed to be out by 4.30am. Just say "Bob the Lorries are all gone" and he will settle!"

What is TOP 5?

TOP 5 is a tool to enable staff to work with carers to tap into their knowledge and expertise of the person who has become the patient.

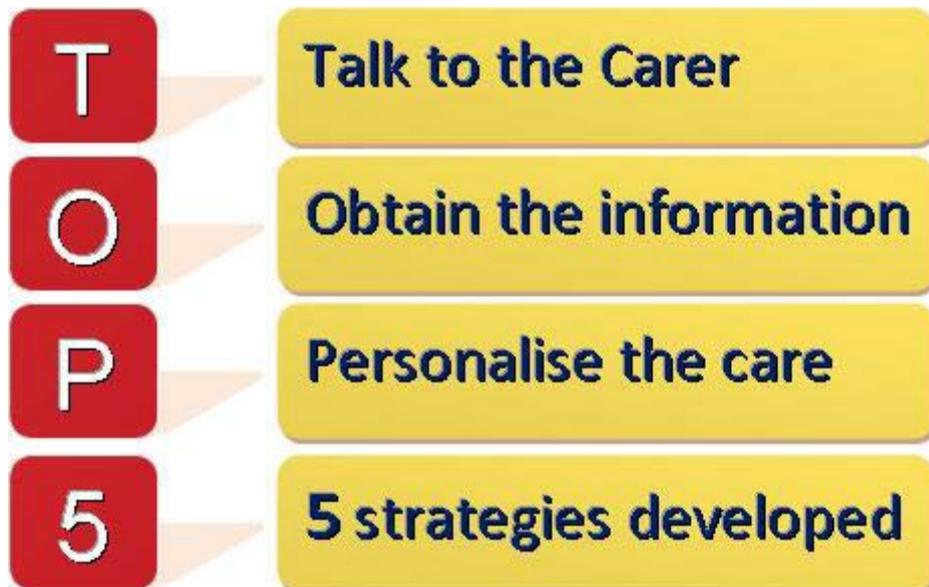
The primary carer's knowledge of the patient, especially in relation to communication and behaviour, can be the key to assisting staff when managing the care of the patient, understanding their needs and providing reassurance in an unfamiliar environment. TOP 5 promotes talking with the carer at the start of an admission and can benefit the patient, carer and staff to effectively manage the patient.

Carers say: "Staff should know if my wife starts to mumble and talk to herself she is becoming anxious – a calm reassurance from staff like 'it's okay Beryl, you are safe. We are looking after you,' is all she needs."
Rex – carer for wife



TOP 5

Just a few easy steps....



TALK with the carer about the person who has become the patient

OBTAIN information about the patient's behaviour, likes, dislikes and interests

PERSONALISE the care to support the patient's sense of self

5 STRATEGIES are then developed between the carer and staff to assist in keeping the patient calm, reassured and engaged

Surname..... MRN.....
Given Names.....
Date of Birth..... Sex.....
(Affix patient label here)



Strategies to Support Care and Communication

Please keep this form in a central place where staff can access it. If the individual is in hospital, place the form on top of the bed chart notes. The TOP 5 form should travel with the individual if transferred to a health care service or to their home.

1.

2.

3.

4.

5.

Carer Name:

Date:

Staff Member:

Date:

The Clinical Excellence Commission would like to acknowledge the Carer Support Unit, Central Coast Local Health District for the integration of their concept and materials to support the further uptake of the TOP 5 initiative. The Clinical Excellence Commission would also like to acknowledge the support of the HCF Health and Medical Research Foundation.



Identifying TOP 5 strategies

As a staff member you should negotiate with the carer the TOP 5 strategies which could be most effective in the setting where the person is being cared for. When initiating a TOP 5 on a person with dementia/memory or thinking problems, the following script can be used as a prompt to obtain strategies from carers.

The following questions are about the person that you care for and will assist with personalising their care.

- **Are there things/situations that you know of that may cause distress?**
e.g. colours, topics, gender of staff, visitors
- **If unsettled, are there words or actions that will help settle and calm?**
e.g. listening to music, relocation, reading and lighting, cup of tea, read the paper
- **Are there any set routines that have been developed to help keep the person reassured?**
e.g. at bedtime, with meals, personal care, when taking medication
- **Are there any repetitive questions or recurring 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 a pet
- **Are you aware of any signs or triggers that indicate a need or a want?**
e.g. fidgeting to indicate a need to go to the toilet



TOP 5 Identification Tag Process

When a patient is identified as being suitable for TOP 5 and the carer and staff member have developed up to 5 strategies, staff should complete the:

TOP 5 'Strategies to Support Care and Communication' form

Place the document into the clinical notes.

Place a '**TOP 5 tag**' on the top of the bedside notes or clinical notes, so that all staff that interact with the patient will be aware that within the notes, **strategies to support care of and communication with that patient**, are available.

A sticker should be put in the patient's medical record in the progress notes, that is identified as a TOP 5 entry, that documents: **"TOP 5 strategies have been identified and negotiated with the carer (name the relationship e.g. partner, child, friend, neighbour etc.)"**



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2014

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2014

TOP 5: HOSPITALS

INFORMATION FOR STAFF



Integrating carer knowledge to improve care for people with dementia

Introduction

The TOP 5 concept was conceived and piloted in the Central Coast Local Health District (CCLHD). The TOP 5 initiative acknowledges the value of carer information for individuals with dementia and other types of cognitive impairment. TOP 5 uses the recording of the carer's tips or helpful hints for effective communication and supportive care to promote personalised care.

In 2012/2013 the Clinical Excellence Commission (CEC) implemented TOP 5 into public and private hospitals and investigated the integration of carer knowledge by staff into the care of hospitalised patients with dementia. The results showed positive evidence of benefit for patients, carers and staff and for health services.

In 2014/2015 the CEC attained a second grant from the HCF Health and Medical Research Foundation to investigate the use of TOP 5 in 'referral' linkages between hospital services, Residential Aged Care Facilities (RACFs), NSW Ambulance services and community services. Hospitals in the initial study indicated that transition of information between the hospital and linkages such as NSW Ambulance, Community services and RACFs could be beneficial for people with dementia.

Hospitals form a 'hub' conduit for the extension of TOP 5 into associated services. This approach will assist transitions of care and improve communication between services.

Benefits of TOP 5

The CEC initiative indicated that TOP 5 improved treatment outcomes, reduced falls, use of specials and use of anti-psychotics, improved care experience and staff satisfaction.

There is increasing support of good practice to include carers as partners in care including to acknowledge and recognise their unique knowledge about the person who has dementia (Schedule 1, NSW Carers Charter in the Carers Recognition Act 2010 No 20).

How it will work

A local team has been formed to assist in the implementation of the TOP 5 initiative. The local team have considered the areas the TOP 5 initiative will be focused in at the onset and will organise staff training that may be required. Local champions have been identified to assist in the process.



What this means for you

You may come across a patient who is admitted to hospital via ED or the pre-admission clinic with a TOP 5 strategy form in place. This TOP 5 form should be placed in the patient's clinical notes and a sticker placed on the patient's bed chart so that it is clearly visible to all staff.

The TOP 5 strategies can be reviewed by staff and may need minor amendments to adjust for the clinical setting and the patient's condition. The TOP 5 form can be used by all members of the health care team who care for the patient and can travel with the patient once they are discharged (either to another ward, another facility or home).

Alternatively, if a patient with dementia arrives in your ward without a TOP 5 in place, an ASET nurse, Aged Care nurse (or other suitable staff member) may initiate one with the patient and carer. A note can be made in the clinical record to indicate that a TOP 5 has been obtained for this patient.

If an ambulance is required for the patient, a copy of the TOP 5 strategies can be handed over to the paramedic, or patient transport officer who in turn will pass it on to the staff at the receiving facility. Ambulance staff may also utilise the TOP 5 strategies whilst the patient is in their care.

TOP 5 is a few easy steps

Talk to the Carer

Encourages staff to talk to the carers of patients with cognitive impairment at the time of their admission. For patients who are removed from their usual place of residence and are experiencing pain or discomfort, anxiety levels are often high. It may not be easy for staff to communicate effectively or understand the often subtle signs that may indicate a patient's anxiety is escalating. This causes frustration for staff, distress for the carers and of course the patient.

Obtain the Information

It is possible to gain real insight into the patient from a carer and by engaging and gently prompting the carer, staff can obtain cues and tips to understand how the patient communicates and reacts when their routine changes or if they are in a strange environment.

Personalise the Care

The care can be personalised using agreed strategies in caring for the patients to lessen anxiety, distress and provide a safer environment. The carer expertise and knowledge is acknowledged. The staff and carer work as a team to develop actionable strategies to assist in the care of the patient.

5 Strategies Developed

5 strategies are developed after consultation between staff and the carer to ensure that the strategies are workable in the hospital setting. The agreed strategies will be included in the patient's bed chart notes (recorded on an identifiable TOP 5 form) enabling all staff to access this information to support the care provided. Up to five strategies may be recorded, however, in some cases there may be only one or two relevant strategies.

THE TOP 5 INITIATIVE

HOW TO WRITE AN EFFECTIVE TOP 5



TOP 5 strategies should assist any care worker to be able to provide support that is person-centred and specific to the needs of the individual with dementia.

A TOP 5 strategy needs to give the 'WHY'

Follow this statement with the personal preference for care and what 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 bathed or toileted her"

EXAMPLES contacting the WHY, the STRATEGY and the OUTCOME

1. John was a prisoner of war and cannot tolerate the look or smell of rice.

Please ensure that John is noted served rice as he will become very angry and physically aggressive

2. Bill always put the car in the garage around 4:00pm. He can become restless around 4:00pm. Tell him the car is already in the garage and he will settle down.

3. Being well groomed and presentable is important to Dora. Due to her stroke she is unable to brush her hair and drools.

Please make sure that her hair is brushed and she has a wash cloth on her left hand that she can use to wipe her face. She will then be cooperative and happy.

4. Graham was a photographer. He has his camera with him at all times. He will ask you if he can take your photo and likes to take spontaneous 'shots' – however there is no film in his camera. Please cooperate as it maintains his sense of 'self'.

BACKGROUND or the WHY	ACTION or BEHAVIOUR	OUTCOME or CONSEQUENCE
Maria is an independent woman who will not take charity. She needs to have her purse with her so she can 'pay her own way'. Her purse does not contain any real money.	Accept her payment for her meals and medications with her 'fake money'.	Maria will eat her meals and take her medication as requested.
Ken was an aircraft mechanic. He was always good in an emergency.	In Ken wanders into the wrong room and refuses to leave, tell him there is an emergency in Hanger no. 3.	Ken will leave the room immediately and head down the hall. Offer him a cup of tea and he will forget all about the 'emergency'.
Beryl is an anxious lady who is frightened of strangers.	Smile at her as you approach and address her by her first name and in a friendly manner.	Beryl will engage with you and relax.
Elsie loves to listen to music.	Play her CDs out loud or through earphones.	Elsie will be happy and less likely to complain.
Michael has a deep faith and likes to read his bible, however he has very limited vision.	If Michael becomes distressed read an excerpt of passage from his bible.	Michael will settle and become calmer.
Myles is a man who likes to be properly dressed. He always likes to wear his wristwatch.	Before Myles' shower reassure him that you will put his wristwatch back on after he is dry and put his watch back on as soon as possible.	Myles will not become agitated or upset after his shower.



WHEN INITIATING A TOP 5 ON A PATIENT WITH DEMENTIA

With regard to the person you care for:

1. Are there things you know of, that may cause distress to _____

(e.g. Female/male staff, noise, colours, words, clothing, visitors)

2. When _____ is unsettled, are there things /tasks that you do that help settle him/her? (e.g. Photos, trinket box, cup of tea, turn light off, sit in chair, read paper)

3. Are there set routines you have developed that help keep _____reassured?

(e.g. At bedtime, meals, with personal care, taking medication)

4. Are there any repetitive questions or re-occurring issues that may need specific answers?

(e.g. "Where is George?") Who is _____likely to call out for? What is the preferred answer?

5. Are you aware of any signs or triggers, that indicate that _____ may have a need or want something?

(e.g. fidgeting = time for a walk: pointing = need to toilet; singing = turn on/off the radio/TV)

The staff member **negotiates with the carer** the **TOP 5 Strategies** which could be the **most effective** in the setting where the person is being cared for

TOP 5

CLINICAL EXCELLENCE COMMISSION

Erin Gilmore and Melissa Tinsley

August 2014



Background

The burden of dementia

- Third leading cause of death in Australia (second for women)*
- In NSW there are almost 112 000 people living with dementia, which is expected to grow to 132 000 people by 2020*
- Behaviour disturbance is common in dementia > 90% of people with dementia experience behavioural and psychological symptoms of dementia (BPSD) during the course of their illness**
- Distressing for the person, their family/carer and staff, associated with increased admission to residential care, more complications in hospital and increased mortality

* Alzheimer's Australia NSW (<http://www.fightdementia.org.au/about-us/statistics-2.aspx>)

** Drouillard et al. 2013 Therapeutic approaches in the management of behavioural and psychological symptoms of dementia in the elderly
Issue: BCMJ, Vol. 55, No. 2

What is TOP 5?

What is TOP 5?



- Conceived and piloted in hospitals in Central Coast Local Health District
- Clinical Excellence Commission (CEC) granted funding from HCF Medical and Health Research Foundation to implement and evaluate the TOP 5 program in NSW
- Engaging with carers to develop up to 5 non-clinical tips and management strategies to aid communication and support personalised care
- People with cognitive impairment, every person has a history and is unique

TOP 5 is:

T

Talk to the Carer

O

Obtain the information

P

Personalise the care

5

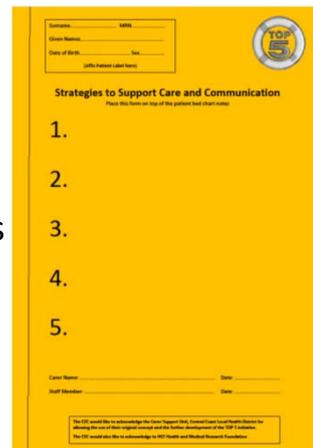
5 strategies developed

Who is the carer?

- A primary carer is a person who takes most responsibility for providing care for the person requiring support.
- Carers can be of any age and from diverse culturally and linguistic backgrounds.
- A carer is a family member, friend, or neighbour who provides care and assistance to another person, who is frail aged, disabled or chronically ill
- A carer can be a member of staff

TOP 5 strategy form

- Once the form has been completed it should travel with them if are transferred home or between services
- As a persons condition changes, the form may need to be reviewed and changed over time
- The TOP 5 strategy form should form part of a person's care plan



The form is a yellow document titled 'Strategies to Support Care and Communication'. It includes a 'TOP 5' logo in the top right corner. The form has fields for 'Patient Name', 'Date of Birth', 'Care Name', and 'Date'. Below these fields is a list of five numbered boxes for strategies. At the bottom, there are fields for 'Care Name' and 'Date', and a small box with text: 'The TOP 5 strategy form is a collaborative tool for staff, carers and patients to develop a care plan for the patient. It is a key part of the patient's care plan and should be reviewed and updated as the patient's needs change. The TOP 5 strategy form is a collaborative tool for staff, carers and patients to develop a care plan for the patient. It is a key part of the patient's care plan and should be reviewed and updated as the patient's needs change.'

Developing the TOP 5 strategies

- TOP 5 strategies should assist any care worker to be able to provide support that is person-centred and specific to the needs of the individual with dementia.
- A TOP 5 strategy needs to give the **WHY**
- Follow this statement with the personal preference for care and what outcome will be if the strategy is/is not followed

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 bathed or toileted her"

PRESENTATION NAME – MONTH YYYY PRESENTER NAME



Ten years of quality and safety

Suggested strategies for TOP 5 form

Communication:

- What to talk about
- How to address the person
- Non-verbal communication cues
- Specific answers required
- Aids to enable communication

Activities:

- Meals
- Medication
- "Must Haves"
- Placement of things, food, drinks
- Behaviour and Routines
- Activities to reassure person

PRESENTATION NAME – MONTH YYYY PRESENTER NAME

10



Ten years of quality and safety

Suggested script

With regard to the person you care for:

1. Are there things you know of, that may cause distress to _____?
(e.g. Female/male staff, noise, colours, words, clothing, visitors)
2. When _____ is unsettled, are there things /tasks that you do that help settle him/her?
(e.g. Photos, trinket box, cup of tea, turn light off, sit in chair, read paper)
3. Are there set routines you have developed that help keep _____ reassured?
(e.g. At bedtime, meals, with personal care, taking medication)
4. Are there any repetitive questions or re-occurring issues that may need specific answers?
(e.g. "Where is George?") Who is _____ likely to call out for? What is the preferred answer?
5. Are you aware of any signs or triggers, that indicate that _____ may have a need or want something?
(e.g. fidgeting = time for a walk: pointing = need to toilet; singing = turn on/off the radio/TV)

TOP 5 TIPS to STRATEGY

Background

One gentleman had been an ambulance officer: all our bells and whistles only escalated his anxiety: with him thinking he needed to jump into action at an 'emergency'. The simple act of discussing all health issues, in a professional exchange, as if we were 'at work' helped a lot. He settled well, and trusted us.

The Strategy

Brian worked as an ambulance officer and whenever he hears a call bell he becomes very anxious. Speak to him as if he is a member of the team using professional terminology and advise that another car is responding. He will then become settled.



TOP 5 TIPS to STRATEGY

Background

Mr G was usually a very gentle and proud man but he became very agitated after his shower. Discussion with his wife told us he became very upset if he did not have his watch on his wrist. She always made sure it was replaced as soon as possible.

The Strategy

Mr G is a man who likes to be properly dressed. He always wears a wristwatch and becomes quite agitated if he is not wearing it. During his shower reassure Mr G that you will put his watch back on after he is dry and put his watch back on as soon as possible. He will not become agitated.



Initial phase

TOP 5 Phase 1 background

- In 2012, TOP 5 was implemented and evaluated in 20 hospital sites across NSW (15 public and 5 private) by the CEC
- The TOP 5 program was mostly implemented within acute aged care settings within the hospitals
- Each hospital site had a local implementation team and were provided with resources and ongoing support from the CEC

Initial TOP 5 sites

- Shellharbour
- Port Macquarie
- Griffith
- Corowa
- Wagga Wagga
- Nepean
- Kyogle
- Prince of Wales
- Sutherland
- Bankstown
- Liverpool
- Royal Prince Alfred
- Dubbo Base
- Orange
- Auburn
- Sydney Adventist Hospital
- Kareena private
- Nimbin
- Urbenville
- The Mater Private
- St Vincents private Hospital

TOP 5 Phase 1- Results



Promising findings:

- ✓ Increase in staff confidence in caring for patients with dementia
- ✓ Acceptability to carers
- ✓ Reduced falls in patients with dementia
- ✓ Reduced use of anti-psychotic medications for patients with dementia
- ✓ Potential cost savings



Ten years of quality and safety

PRESENTATION NAME – MONTH YYYY PRESENTER NAME

17

TOP 5 Phase 2

Grant received from HCF Research Foundation to investigate 'referral linkages' for a period of 12 months.

- Hospitals (10 from original study)
 - Pre-admission clinic
 - Emergency Department
- Residential Aged Care Facilities
- Community services (home)
- NSW Ambulance



Ten years of quality and safety

PRESENTATION NAME – MONTH YYYY PRESENTER NAME

18

How TOP 5 will work across facilities?



Generic principles

- Staff members may come across people with dementia who have a TOP 5 form in place
- The TOP 5 form may need to be adjusted depending on the care setting
- If a person with dementia doesn't have a form in place, a suitable member of staff can commence discussions with the carer around TOP 5
- Staff can provide carers/family members with a TOP 5 brochure and engage with them to obtain up to 5 non-clinical strategies
- The form should follow the person when they are discharged/transferred or admitted to a health care setting - including NSW Ambulance

TOP 5 strategies in hospitals

- TOP 5 strategy form should be placed in the patient's notes.
- The form should follow the patient when they are discharged/transferred to:
 - Another ward
 - Another hospital
 - A Residential Aged Care Facility
 - Their home



TOP 5 strategies from RACF

- A TOP 5 form can be completed with the carer for new and existing residents with dementia or memory/thinking problems
- Alternatively, a staff member who has a close relationship with the resident can provide information to assist with developing the TOP 5 strategies
- New admissions – form completed during this transition period



TOP 5 in community services

- TOP 5 information is kept in the clients home
- Staff members who have a close relationship with the client may assist in developing the TOP 5 strategies
- If the client is transferred anywhere the TOP 5 form will follow the client.



PRESENTATION NAME – MONTH YYYY PRESENTER NAME

23



TOP 5 in NSW Ambulance

- The TOP 5 strategy form should be transferred with the individual with dementia from each facility/service via NSW Ambulance Services (e.g. from RACF to hospital)
- Ambulance staff may utilise the strategies whilst the resident is in their care



PRESENTATION NAME – MONTH YYYY PRESENTER NAME

24



Key outcomes for staff

- Optimise discharge planning
- Assist with time management
- Safer work environment
- Increase work satisfaction

"I can see the benefits for my patients"
Staff (MLHD)

"If I spend 5 minutes now it might save hours of anxiety later"
Staff (NNSW LHD)

"It's something I do but have never formalised"
Staff (NBMLHD)

Staff comments

"Easy to manage patients with involvement of family and knowing their likes and needs prior to them having the condition".

"Since TOP 5 arrived I feel more confident in dealing with both patient & carer".

"TOP 5 has helped me with a few patients when they have become agitated. It is also nice to speak with the carers & find out more about their loved ones".



"TOP 5 is a good initiative where we can learn more about the dementia patient via communicating with the family".

"A great program. So simple but effective".

Carers can benefit:



- increased confidence that the individual with dementia will be more settled and comfortable when they are not at the bedside
- increased confidence in the health care provided.
- feel respected and valued with regard to their knowledge.
- have been acknowledged as a partner in care.



Carers can benefit:

“When I left my uncle last night I was so worried as he was more distressed than I had ever seen him. After speaking with staff about TOP 5 when I came in the next day I saw that the staff had listened, passed information on to the next shift and used the things I had spoken about. My uncle was still ill but had settled. What a comfort that was to my aunt! Thankyou.”

Family member (WSLHD)

Carer comments



“Thankyou for best caring. I felt very comfortable leaving him at night.”

“Good system that tries to keep patient comfortable in unfamiliar surroundings”.

“TOP 5 is invaluable as it makes staff aware of the patient's humanity & individuality”.

“I think this is a great initiative for patients, staff and carers. It allows patients to settle more easily, staff to get to know patients more and alleviates stress for all”.

“We didn't offer a lot but they used what we gave them”.

PRESENTATION NAME – MONTH YYYY
PRESENTER NAME

29



Key outcomes for people with dementia

- Clinical evaluation indicators (decrease in falls, use of restraint, incidence of aggressive behaviour)
- More comfortable in unfamiliar surroundings
- Humanity and individuality recognised by staff
- Less agitation, distress and frustration



PRESENTATION NAME – MONTH YYYY PRESENTER NAME

30



Next steps

- Local discussions
- Local teams
- Local governance structures
- Ongoing communication with CEC
- Role play... your turn.

Thank you – Questions?

Acknowledgements:

TOP 5 is an initiative developed in the Central Coast Local Health District (CCLHD, NSW). This TOP education was designed to support the implementation and adoption of the TOP 5 concept within hospitals, Residential Aged Care Facilities and community facilities and draws on materials developed in the CCLHD.

For further information:

patientbasedcare@cec.health.nsw.gov.au

www.cec.health.nsw.gov.au



Communicating with people who have memory and thinking difficulties

- ✓ Introduce yourself, every time you go to the patient
- ✓ Maintain eye contact, if this is appropriate for the culture
- ✓ Be calm and do not rush
- ✓ Talk gently and matter-of-fact
- ✓ Keep sentences short and simple
- ✓ Focus on one instruction at a time
- ✓ Allow time for the patient to respond
- ✓ Repeat yourself... do not presume you have been understood
- ✓ Do not give multiple choices
- ✓ Always involve the carer and use their knowledge of the patient

TOP 5 is:

- ✓ Simple, flexible and adaptable
- ✓ Person based and personalised
- ✓ Reassuring for carers, patient and staff
- ✓ Integrates the carer's knowledge into the patient's journey



Are you a CARER?

Do you care for someone with memory and thinking problems?

You can help us improve their care whilst in hospital.

Patients with thinking problems can feel DISORIENTED, FRIGHTENED and CONFUSED.

Often families and carers have valuable information about patients that could aid health care professionals.

TOP 5 is: a program created to promote better communication between health staff and carers. TOP 5 uses the knowledge of a carer or a family member has about the patient and implements the knowledge to settle and reassure the patient in a hospital setting.



Talk to a staff member today about TOP 5 and find out how you can help us care for your loved one while they are in hospital

Do you care for a person with memory or thinking problems?

We need your knowledge!

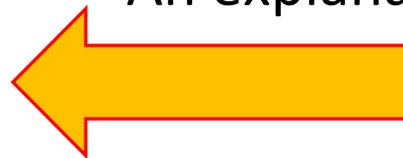
We want to discuss with you and decide on what will assist staff to provide care in hospitals and write up to 5 strategies on the TOP 5 form



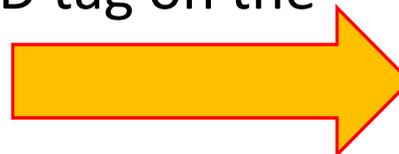
Form titled "Strategies to Support Care and Communication" with a yellow background. It includes fields for Surname, Given Names, Date of Birth, Sex, Carer Name, and Staff Member. It features a numbered list from 1 to 5 for writing strategies. A "TOP 5" logo is in the top right corner.

Brochure titled "Carer TOP 5 information" with a "Partnering with Patients" logo. It includes sections: "Who is a carer?", "What does a carer do?", "Thank you for sharing your information with us.", "For more information contact:", and "Facility Logo". It features a "TOP 5" logo and a photo of a carer assisting an elderly person.

An explanation brochure will be provided



And, so staff know to look for the TOP 5 strategy form, we place a TOP 5 ID tag on the front of the bed chart or folder



T Talk to the Carer
O Obtain the information
P Personalise the care
5 5 strategies developed
Clinical Excellence Commission

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HOW TO WRITE AN EFFECTIVE TOP 5

A TOP5 strategy needs to give the **WHY**

e.g. **“Bill always put the car in the garage around 4pm so he can become restless at 4ish.**

Follow this statement with the **personal preference for care** and what **the outcome** will be if the tip is or is not followed
e.g.

“Tell him the car is already in the garage, and he will settle down”.

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**TOP 5
STAFF PRE-IMPLEMENTATION SURVEY**



Date

Position Title

Doctor Nurse Allied health professionals Other.....

1. How would you describe your overall knowledge of dementia?

None/Little Some Good Excellent

2. How confident are you in managing a patient with dementia/cognitive impairment?

None/Little Some Average Extremely

3. Are you satisfied that your department provides you with the following?

a. Information to care for a patient with dementia Yes No

b. Support to care for a patient with dementia Yes No

c. Education tools to care for a patient with dementia Yes No

4. If a carer provided information about personalising care for an individual how would you transfer this information? (e.g. to a team member/hospital/ambulance)?

Verbal Written None

Other _____

5. How important do you think it is to involve a carer in managing a patient with dementia?

None/Little Some Average Extremely

**Thank you for your time in completing this survey.
Please place your completed response in the envelope provided.
If you have any questions, please contact the TOP 5 Liaison Person**



TOP 5
STAFF POST-IMPLEMENTATION SURVEY
 Conducted at 6 and 12 months



Date

Position Title

Doctor Nurse Allied health professionals Other.....

1. How would you describe your overall knowledge of dementia?

None/Little Some Good Excellent

2. How confident are you in managing a patient with dementia/cognitive impairment?

None/Little Some Average Excellent

3. Are you satisfied that your facility provides you with the following?

- a. Information to care for a patient with dementia? Yes No
- b. Support to care for a patient with dementia? Yes No
- c. Education tools to care for a patient with dementia? Yes No

4. Whilst caring for a patient with dementia, how would you rate your work satisfaction level?

Not at all satisfied Slightly satisfied Moderately satisfied Extremely satisfied

5. If a carer provided information about personalising care for an individual, how would you transfer this information? (e.g. to a team member/hospital/ambulance)?

TOP 5 Form Verbal 'Other' Written None

6. How important do you think it is to involve a carer in managing a patient with dementia?

None/Little Some Average Extremely

7. How confident are you in engaging with carers in discussions about dementia/cognitive impairment?

None/Little Some Average Extremely



8. Are you aware of the 'TOP 5' process? Yes No

9. Have you attended an education session on 'TOP 5'? Yes No

10. Could you please explain in your own words your understanding of 'TOP 5'?

11. Have you initiated a 'TOP 5' for a patient?
 Yes No → go to Question 17

12. How easy did you find it to identify patients who could potentially benefit from having a 'TOP 5'?

Very difficult Some difficulty Easy Very easy

13. Who was the 'TOP 5' information obtained from?
 Staff Patient Family/Carer

Other _____

14. How easy was the 'TOP 5' process to implement and/or use?
 Very difficult Some difficulty Easy Very easy

15. Was the 'TOP 5' process time consuming?
 Yes No

16. Did you use any of the TOP 5 strategies whilst caring for the patient?
 Yes No

17. Have you received or cared for any patients with dementia/cognitive impairment who had 'TOP 5' strategies already in place?
 Yes No → (If you answered yes to Question 11 → go to Question 21)
 (If you answered no to Question 11 → **end of survey**)



18. Where was this patient transferred from?

Ward Residential Aged Care Facility Community service Other Unknown

19. How was this information typically received?

TOP 5 form Written Verbal Other _____

20. 16. Did you use any of the TOP 5 strategies whilst caring for the patient?

Yes No

21. For a patient with a 'TOP 5', did you feel:

- a. Patient became less agitated and distressed? Yes No
- b. Patient was more cooperative? Yes No
- c. Less restraint (chemical) was required for the patient? Yes No
- d. Less need to 'special' patients? Yes No
- e. Carers appeared confident/satisfied with the care provided? Yes No
- f. Less concern raised by family/carer? Yes No

22. For patients with a 'TOP 5', were you better able to manage the patient in the hospital environment?

Yes No

23. When the patient was transferred from ED (either internally or externally) was the 'TOP 5' information passed on/shared?

Yes No → to go Question 27 Don't know → to go Question 27

24. How was the 'TOP 5' information communicated/passed on/shared?

TOP 5 form 'Other' Written Verbal Don't know

Other _____

25. Who was the 'TOP 5' information passed on to?

Doctor Nurse Allied health professionals Residential Aged Care Facility
Paramedic Carer Don't know

Other _____



26. How successful do you think the transfer of this 'TOP 5' information was to the other ward/facilities

Poor Fair Good Very Good

27. Overall would you say 'TOP 5' is an effective strategy in managing patients with dementia?

Yes No

Please comment:

**Thank you for your time in completing this survey.
Please place your completed response in the envelope provided.
If you have any questions, please contact the TOP 5 Liaison Person**



Information and Consent Form for Carer Feedback

The TOP 5 initiative encourages staff to seek information from a patient's carer in order to identify helpful hints & strategies that can be used to lessen the anxiety of patients and carers and gain a better understanding of how the patient/resident would typically react and communicate in their environment.

We are seeking your assistance to find out if the "TOP 5" initiative will have an impact on participating carers and staff by providing a tool that meets the individual needs and preferences of the patients in these facilities. Part of the evaluation will include a brief survey, this aims to identify the impact and effectiveness of sharing this TOP 5 information between services.

What are you asking me to do?

Using a short, anonymous and de-identified survey we would like to ask a few questions of you as a carer for a person with dementia. You will be asked to sign a consent form to allow your information to be used confidentially for the purpose of further analysis.

Should you wish to have further assistance in completing the survey, please ask the staff member who provided you with the survey form.

What happens to the information I provide?

The completed surveys will be placed in a sealed envelope and used for analysis. Your information will be kept completely confidential and the content will not identify you or your loved one in any way.

What should I do if I would like further information regarding this survey before I decide to participate?

If you:

- Have questions which were not resolved to your satisfaction by the staff;
- Require broader information regarding the initiative;
- Wish to make a complaint about the survey; or,
- Require any further additional information

Please contact the name of the site/facility contact contained on the other side of this form.

Thank you for taking the time to consider sharing your experience within the NSW health system.

Site Liaison	
Name:	
Contact No:	

Consent Section

Primary Carer

NOTE: This form will be collected by the TOP 5 Site Liaison Person and will remain with the hospital site for their records

I agree to take part in the research study as specified. I have had the initiative explained to me, and I have read the Participant Information Sheet. I understand that agreeing to take part means that:

I agree to complete the survey with the questions being clarified if required by the TOP 5 Site Liaison Person

Yes No

I understand that my participation is voluntary, that I can choose not to participate in part or all of the study, and that I can withdraw at any stage of the study without being penalised or disadvantaged in any way.

I understand that any data that the researcher extracts from the questionnaire for use in reports or published findings will not, under any circumstances, contain names or identifying characteristics.

I understand that any information I provide in this questionnaire is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the study, or to any other party.

I understand that data from the questionnaire will be kept in a secure storage and accessible to the research team. I also understand that the data will be destroyed after a five (5) year period unless I consent to it being used in future research.

Participant's name: _____

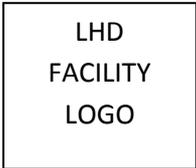
Signature: _____

Date: _____



TOP 5 CARER SURVEY

To be completed – by carers involved in the TOP 5 initiative



You have been asked to provide feedback about the TOP 5 initiative. Our staff will have approached you shortly after admission to gain valuable information from the knowledge and expertise you have in caring for the person who has become our resident. We are interested to know how you feel about the TOP 5 program and ask that you please think about this when completing the following information. Be assured that your comments will be kept **confidential**.

Name of Facility (if applicable) _____

1. Were you approached by a member of staff in regards to the TOP 5 process for gaining personalised ‘tips’ from carers about caring for a resident?

Yes No

2. How satisfied were you with the information you were given about ‘TOP 5’?

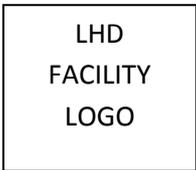
Very dissatisfied Dissatisfied Unsure Satisfied Very satisfied

3. Did you provide ‘tips’ for staff to use when caring for the resident?

Yes No

Please provide your opinion for each statement:

	Disagree	Unsure	Agree	Strongly agree
4. Staff acknowledged and used the ‘TOP 5’ suggestions you made when providing care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. In your opinion, your loved one/the resident has been calmer and less anxious as a result of the implemented ‘TOP 5’ strategies.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. The staff have communicated well with my loved one/the resident.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. The use of ‘TOP 5’ by staff has increased my confidence in the staff who are looking after my loved one/the resident.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



	Disagree	Unsure	Agree	Strongly Agree
8. I feel more engaged with staff and involved in the care as staff are aware of the importance of my role in caring for the resident.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. To the best of my knowledge, I believe my suggested TOP 5 strategies were implemented effectively, and my loved one/the resident benefited as a result.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Thank you for your time in completing this survey.
Please place your completed response in the envelope provided.
If you have any questions, please contact the TOP 5 Liaison Person**

The Clinical Excellence Commission would like to acknowledge the Carer Support Unit, Central Coast Local Health District for the integration of their concept and materials to support the further uptake of the TOP 5 initiative. The Clinical Excellence Commission would also like to acknowledge the support of the HCF health and Medical Research Foundation.