

# TOP 5 Toolkit



## Residential Aged Care Facilities

Integrating carer knowledge to improve care for  
residents 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).

Individuals living with dementia, their families and carers are increasingly being recognised as important members of the health care team. Often carers have valuable information about individuals that they care for, 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 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 resident 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 carer's knowledge in achieving this. Overall analysis of the CEC program indicated 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 individuals with dementia, carers and staff and provides a safer environment for all concerned.

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

- 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)
- 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)

The Residential Care Accreditation Standards and Accreditation, developed by the Australian Aged Care Quality Agency, includes Standard 2 "Health and Personal Care" which states a resident's mental and physical health will be promoted and achieved at the optimum level, in partnership between each resident (or his or her representative) and the health care team. This standard provides the framework for residents (or their representatives) to be invited to be involved in the development of the resident's care plan that will identify the needs, problems and strategies and goals or expected outcomes.

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 facilities to put in place a local team to support introducing a sustainable approach to TOP 5.

## The role of local leadership

At each RACF, 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 – a senior clinician who can champion the TOP 5 initiative and help engage local clinical staff
- Local Site Liaison – a committed and enthused individual who will act as the local contact for the CEC and 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?

A TOP 5 form can be completed for all new and existing residents with a memory or thinking problem. Members of staff will be asked to provide carers of residents with dementia with a TOP 5 brochure (see Appendix C) and engage with them to obtain their TOP 5 (non-clinical) tips to assist the team to communicate and manage the resident's care.

Alternatively if staff members have a close relationship with a resident and have come to know a residents personality over time, staff also may be able to assist in developing the TOP 5 strategies for that resident.

If a resident is a new admission to your facility, a TOP 5 form can be completed on admission with the carer during this transition period (please refer to Appendix B).

The tips and subsequent strategies obtained from the carer or staff member should be recorded on the TOP 5 strategy form (see Appendix E), and either kept in the resident's bedroom or in a centralised location for all staff to access. This TOP 5 information can be included in the residents care plan which will enable all staff to access this information and support the resident's care.

Once the TOP 5 strategies have been developed, place a TOP 5 tag (see Appendix G) at the top of the residents care plan, so that all staff that interact with the resident will be aware that strategies to support care of and communication with that resident, are available within the care plan.

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

If the resident needs to go to hospital, a copy of their TOP 5 strategies should go with them. Hospital staff will adapt these TOP 5 strategies to suit the clinical environment. Similarly, if the resident is going home, they should take the TOP 5 strategy form with them.

If an ambulance is required for the resident, 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 hospital or destination. 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 resident, it is considered an opportunity to 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.

## How will we 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 Residential Aged Care Facilities

Appendix C –TOP 5 Brochure for Carers in Residential Aged Care Facilities

Appendix D – TOP 5 Poster for use in the facility

Appendix E – TOP 5 Strategy Form

Appendix F – TOP 5 ID Process and ID Tags

Appendix G - TOP 5 Sticker for resident's 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 Poster for Carers

Appendix N – TOP 5 Lanyards for staff

## EVALUATION TOOLS:

Appendix O – TOP 5 Pre-implementation Staff Survey Form

Appendix P– TOP 5 Post-implementation Staff Survey Form

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 residents with dementia. TOP 5 will embody the principles of partnership and recognise carers and residents as key members of the care team. This will be evidenced by:

1. Informing carers of residents 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 jointly 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 and residents to personalise the care

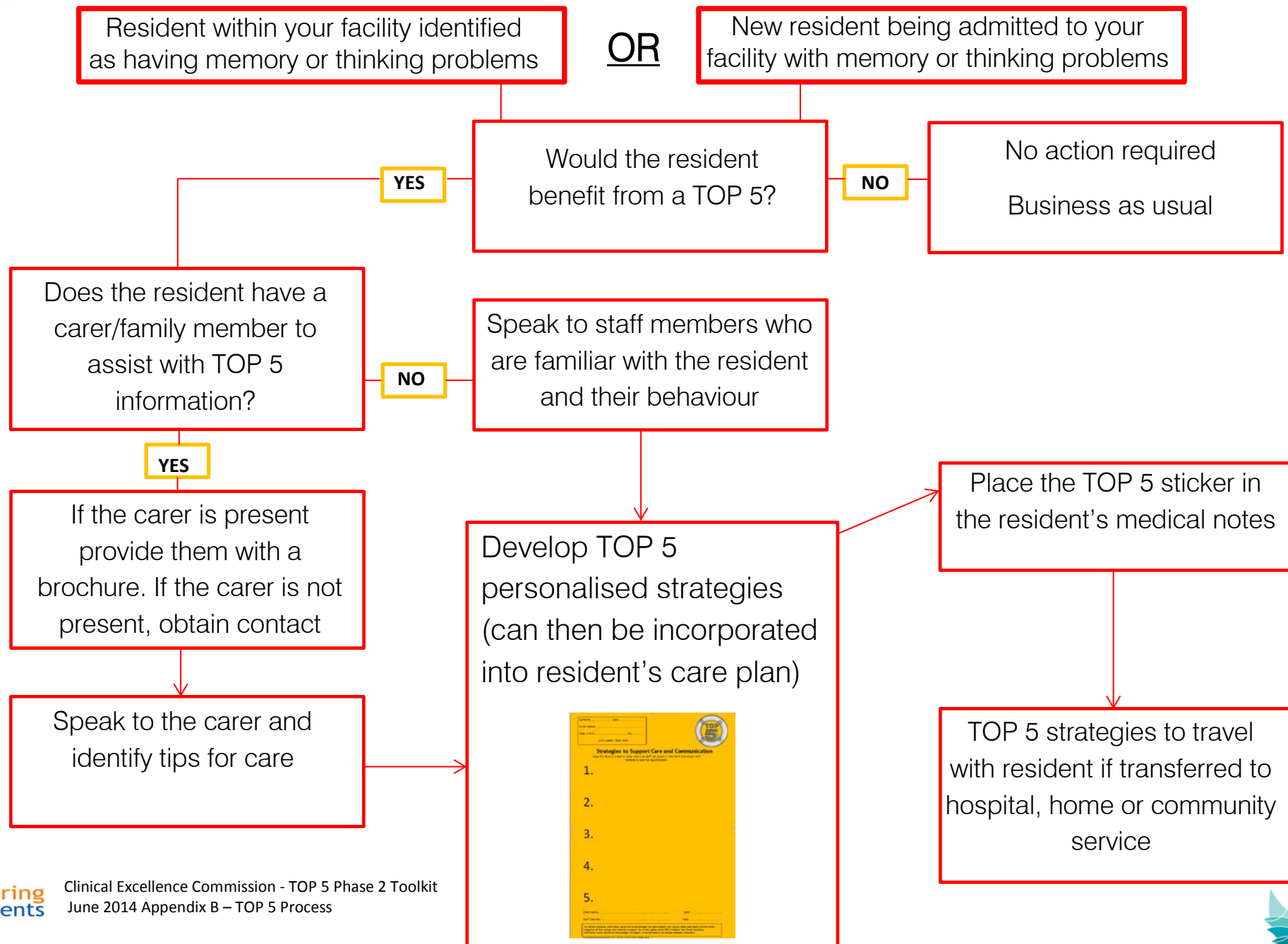
## Caring for all

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 residents who have cognitive impairment.
9. Every time TOP 5 is initiated it should be seen as an opportunity to improve the quality of care and communication to benefit residents, 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 and Medical Research Foundation.

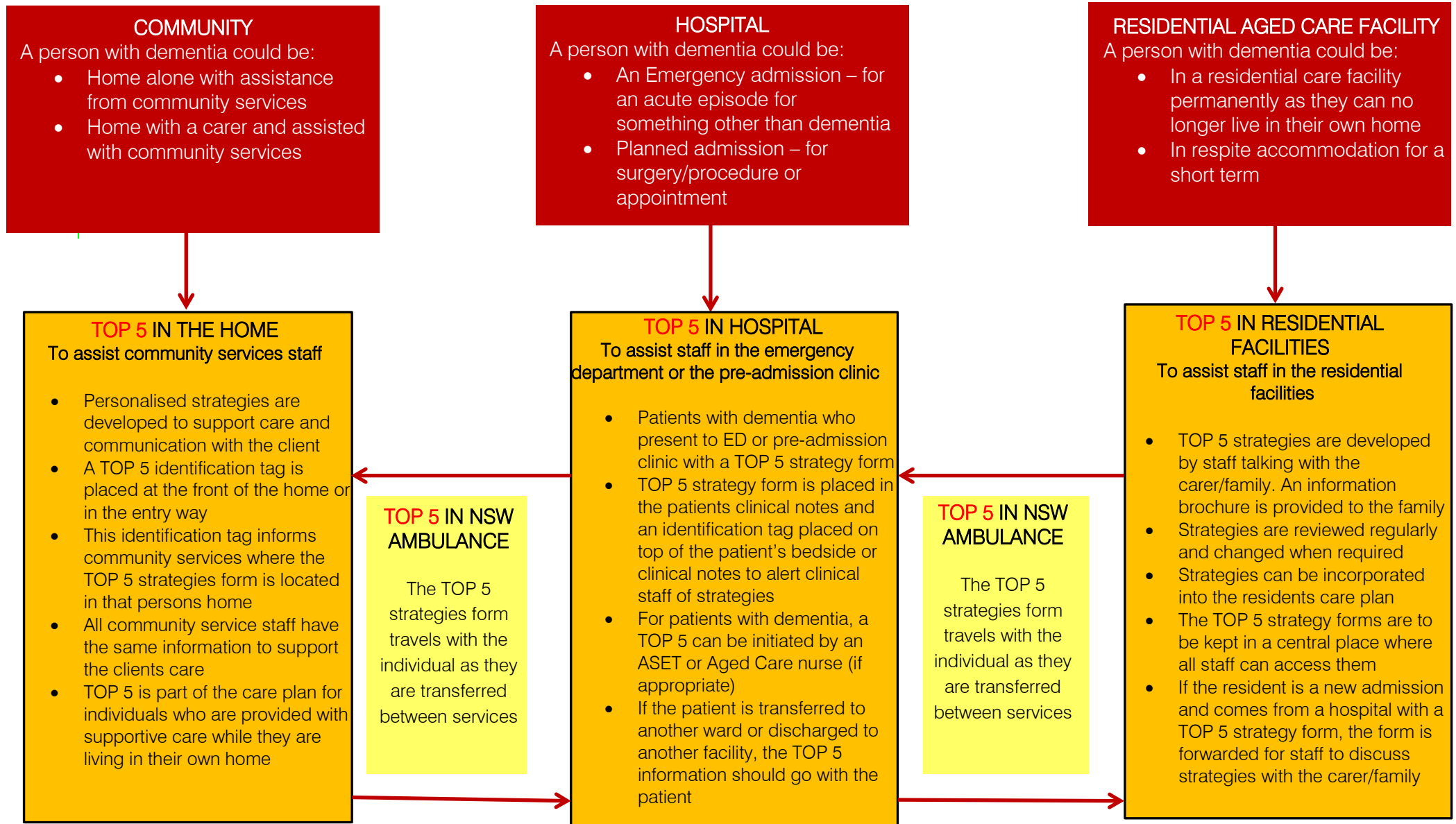


# TOP 5 PROCESS – RESIDENTIAL AGED CARE FACILITIES





# 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 resident.

## 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

RESIDENTIAL AGED CARE



**TOP 5 helps to personalise care for residents 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**



**This information is called**

This information (also referred to as strategies) will be included in the residents care plan which will enable all staff to access this information and support the resident's care.

If the person that you care for needs to go to hospital, a copy of their TOP 5 strategies will go with the resident. Hospital staff will adapt these TOP 5 strategies to suit the clinical environment.

If an ambulance is required for the resident, a copy of the TOP 5 strategies will be handed over to the paramedic, who in turn will pass it on the staff at the receiving hospital. Ambulance staff may also utilise the TOP 5 strategies whilst the resident is in their 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 that enables staff to work with carers to tap into their knowledge and expertise of the person who has become the resident.

The carer's knowledge of the resident, especially in relation to communication and behaviour, can be the key to assisting staff when managing the care of the resident, understanding their individual needs and providing reassurance in an unfamiliar environment.

## What will happen?

The resident will have been identified as having memory or thinking problems. The staff member will talk with you about TOP 5 and explain how it can help with the resident's care. They will ask you about the five most important things staff should know to communicate, support and reassure the resident.

**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 resident

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

**PERSONALISE** the care to support the resident's sense of self

**5 STRATEGIES** are then developed between the carer and staff to assist in keeping the resident 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 resident 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 in a central place where all staff can access it.

Place a '**TOP 5 tag**' in the resident's care plan, so that all staff that interact with the resident will be aware that within the care plan, **strategies to support care of and communication with that resident**, are available.

A sticker can be placed in the resident's care plan that identifies a TOP 5 entry, that documents: **"This resident has a TOP 5 strategy in their notes to assist with their care."**



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 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.

2014

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.

2014

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.

2014

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.

2014

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.

2014

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.

2014

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.

2014

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.

2014







# TOP 5: RESIDENTIAL AGED CARE FACILITIES

## 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.

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 be asked to engage with carers to obtain their TOP 5 tips to assist the team to communicate and manage the resident's care. Alternatively if staff members have a close relationship with a resident and have come to know a residents personality over time, they also may be able to assist in developing the TOP 5 strategies for that resident. The tips and subsequent strategies obtained from the carer or staff member can be recorded on the TOP 5 strategy form and either kept in the resident's bedroom or in a centralised location for all staff to access. This information (also referred to as strategies) can be included in the residents care plan which will enable all staff to access this information and support the resident's care.

If the resident needs to go to hospital, a copy of their TOP 5 strategies can go with them. Hospital staff will adapt these TOP 5 strategies to suit the clinical environment.

If an ambulance is required for the resident, 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 the staff at the receiving facility. Ambulance staff may also utilise the TOP 5 strategies whilst the resident is in their care.

## TOP 5 is a few easy steps

### Talk to the Carer

Encourages staff to talk to the carers of residents with dementia at the time of their admission. For residents 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 residents anxiety is escalating. This causes frustration for staff, distress for the carers and of course the resident.

### Obtain the Information

It is possible to gain real insight into the resident from a carer, and by engaging and gently prompting the carer, staff can obtain cues and tips to understand how the resident 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 residents 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 resident.

### 5 Strategies Developed

5 strategies are developed after consultation between staff and the carer to ensure that the strategies are workable in the setting where the resident is being cared for. The agreed strategies can be included in the resident's care plan (recorded on an identifiable TOP 5 form) enabling all staff to access this information to support the care provided. Up to 5 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 RESIDENT 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

PRESENTATION NAME – MONTH YYYY PRESENTER NAME

3



# What is TOP 5?

PRESENTATION NAME – MONTH YYYY  
PRESENTER NAME

4



# 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

Surname: _____ Given Name: _____ Date of Birth: _____ Sex: _____ (affix stamped label here)	
--	---

## Strategies to Support Care and Communication

Place this icon on top of the printed test chart cover



- 1.
- 2.
- 3.
- 4.
- 5.

Color Marker \_\_\_\_\_  
 Staff Member \_\_\_\_\_

Date \_\_\_\_\_  
 Date \_\_\_\_\_

The CDC would like to acknowledge the Center Support Unit, Central Case Investigation Division for  
 allowing this use of their copyright material on the Center Development of the TOP 5 Evidence  
 The CDC would like to acknowledge the 2017 Health and Medical Research Foundation

## 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



## 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



# 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)

PRESENTATION NAME – MONTH YYYY PRESENTER NAME

11



## 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.



PRESENTATION NAME – MONTH YYYY  
PRESENTER NAME

12



## 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.



PRESENTATION NAME – MONTH YYYY  
PRESENTER NAME

13

# Initial phase

PRESENTATION NAME – MONTH YYYY  
PRESENTER NAME

14

# 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    | • Liverpool                    |
| • Port Macquarie  | • Royal Prince Alfred          |
| • Griffith        | • Dubbo Base                   |
| • Corowa          | • Orange                       |
| • Wagga Wagga     | • Auburn                       |
| • Nepean          | • Sydney Adventist Hospital    |
| • Kyogle          | • Kareena private              |
| • Prince of Wales | • Nimbin                       |
| • Sutherland      | • Urbenville                   |
| • Bankstown       | • 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



PRESENTATION NAME – MONTH YYYY PRESENTER NAME

17

Ten years of quality and safety

# 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



PRESENTATION NAME – MONTH YYYY PRESENTER NAME

18

Ten years of quality and safety

## How TOP 5 will work across facilities?



PRESENTATION NAME – MONTH YYYY PRESENTER NAME

19

## 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

PRESENTATION NAME – MONTH YYYY PRESENTER NAME

20



## 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".

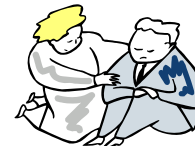
PRESENTATION NAME – MONTH YYYY  
PRESENTER NAME

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](mailto:patientbasedcare@cec.health.nsw.gov.au)

[www.cec.health.nsw.gov.au](http://www.cec.health.nsw.gov.au)





## Communicating with people who have memory and thinking difficulties

- ✓ Introduce yourself, every time you go to the resident
- ✓ 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 resident 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 resident





## TOP 5 is:

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





# Are you a CARER?

## Do you care for someone with memory and thinking problems?

You can help us improve their care whilst they are in a residential aged care facility.

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

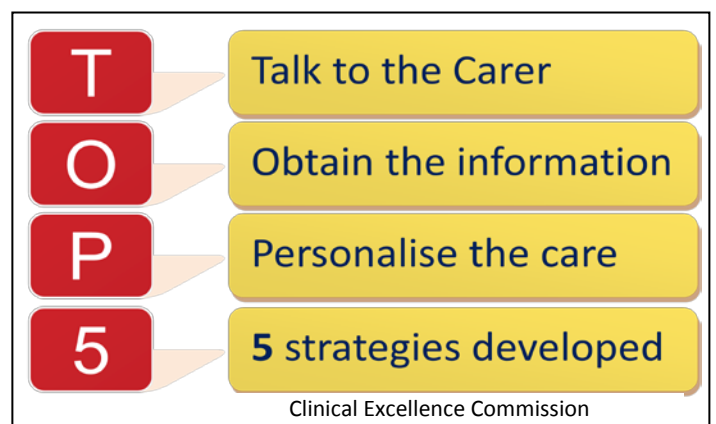
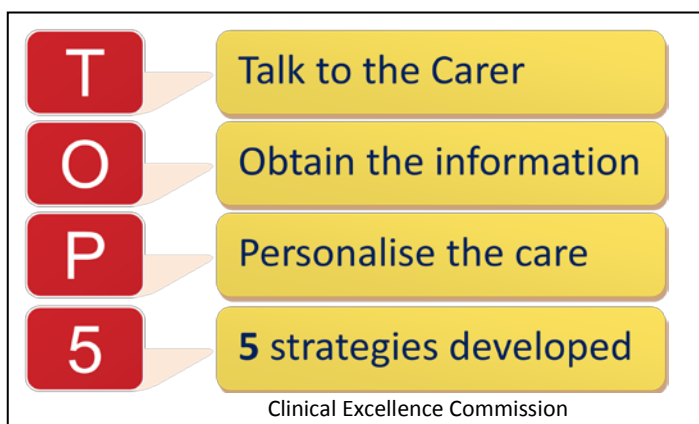
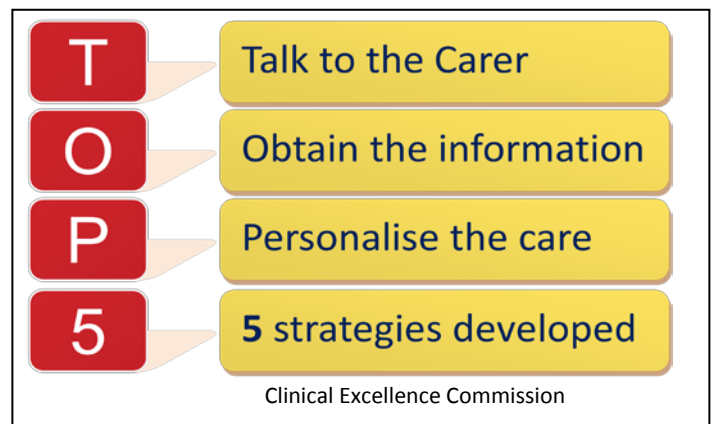
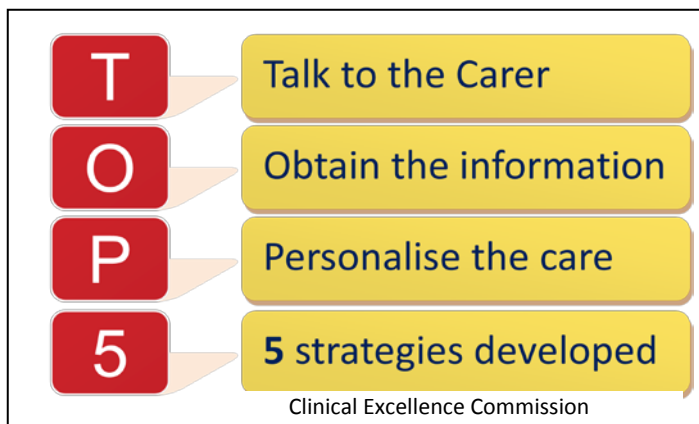
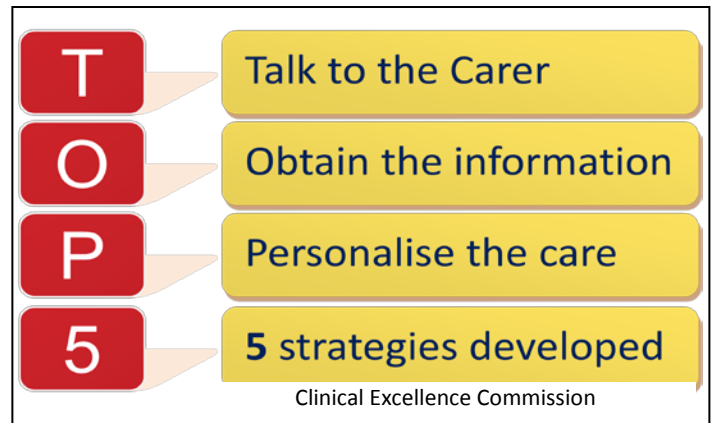
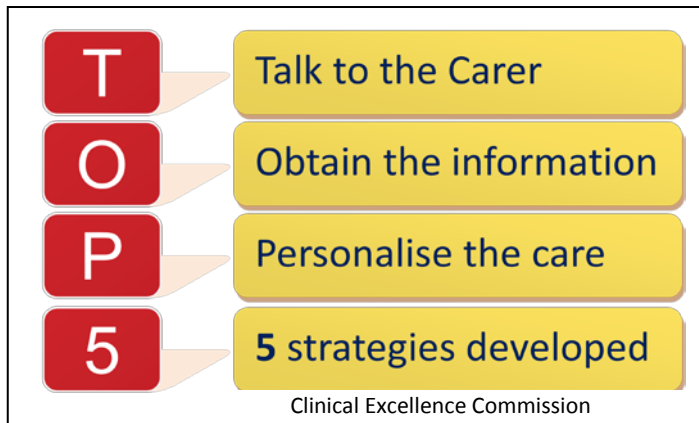
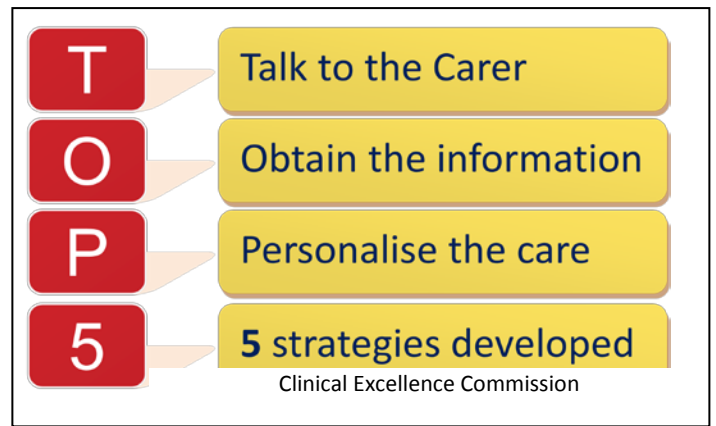
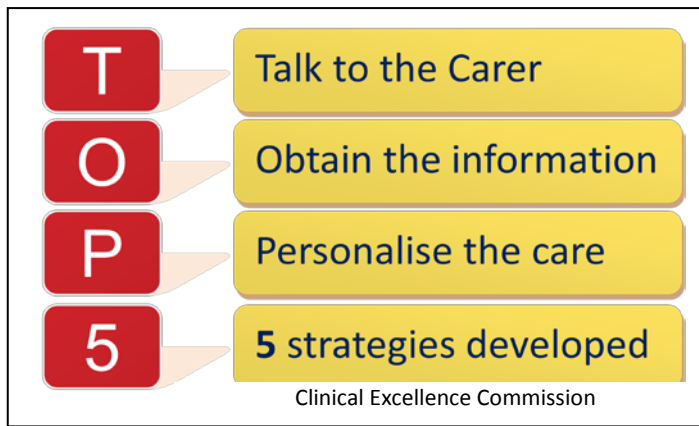
Often families and carers have valuable information about residents that could aid health care professionals.

**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 resident and implements the knowledge to settle and reassure the resident in a residential 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 a residential facility**





### 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".**

### 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".**

### 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".**

### 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".**

### 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".**

### 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".**

### 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".**

### 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".**



**TOP 5**  
**STAFF PRE-IMPLEMENTATION SURVEY**  
**(Residential Aged Care Facility)**

LHD  
FACILITY  
LOGO

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 resident with dementia?

None/Little ☐ Some ☐ Average ☐ Extremely ☐

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

a. Information to care for a resident with dementia Yes ☐ No ☐

b. Support to care for a resident with dementia Yes ☐ No ☐

c. Education tools to care for a resident 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 ☐

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

None/Little ☐ Some ☐ Average ☐ Extremely ☐

6. How confident are you in engaging with carers in discussions about 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  
**(Residential Aged Care Facilities)**

LHD  
FACILITY  
LOGO

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

4. Whilst caring for a resident 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)?

TOP 5 form ☐ Verbal ☐ 'Other' written ☐ None ☐

6. How important do you think it is to involve a carer in managing a resident 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 resident/s?

Yes ☐

No ☐ → go to Question 17

12. How easy did you find it to identify residents 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 ☐

Resident ☐

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 or implement the 'TOP 5' strategies as part of the resident's care plan?

Yes ☐

No ☐

17. Have you received, cared for, or know of a resident with dementia/cognitive impairment that already had TOP 5 strategies in place?

Yes ☐

No ☐ → (If you answered yes to Question 11 → go to Question 19)  
(If you answered no to Question 11 → **end of survey**)

18. Did you use any of the TOP 5 strategies or implement the 'TOP 5' strategies as part of the resident's care plan?

Yes ☐

No ☐



19. For residents with a 'TOP 5' implemented, did you feel:

- |  |                              |                             |
|--|------------------------------|-----------------------------|
| a. The resident became less agitated and distressed?           | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| b. The resident was more cooperative?                          | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| c. Less restraint (chemical) was required for the resident     | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| d. Carers appeared confident/satisfied with the care provided? | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| e. Less concerns were raised by family?                        | Yes <input type="checkbox"/> | No <input type="checkbox"/> |

20. For residents with a 'TOP 5', were you better able to manage the resident in their environment?

Yes ☐ No ☐

21. Are you aware if any of your residents with a 'TOP 5' in place have been transferred to another facility (e.g. hospital)?

Yes ☐ No ☐ → go to Question 26

22. When the resident was transferred to other health services/facilities (e.g. hospital/ambulance) was the 'TOP 5' information passed on/shared?

Yes ☐ No ☐ → go to Question 26 Don't know ☐ → go to Question 26

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

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

Other \_\_\_\_\_

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

Doctor ☐ Nurse ☐ Allied health professionals ☐  
Paramedic ☐ Carer ☐ Don't know ☐ Other \_\_\_\_\_

25. How successful do you think the transfer of this 'TOP 5' information was to the external facility/service?

Poor ☐ Fair ☐ Good ☐ Very Good ☐

26. Did your facility ever receive a resident back from a hospital or other service, accompanied by a TOP 5 form to provide personalised 'tips' for care?

Yes ☐ No ☐ → go to Question 29 Don't know ☐ → go to Question 29



LHD  
FACILITY  
LOGO

27. Where was this resident transferred from?

Hospital ☐ Residential Aged Care Facility ☐ Community service ☐ Their home ☐  
Other ☐ Unknown ☐

28. How was this information typically received?

TOP 5 form ☐ Written ☐ Verbal ☐ Other \_\_\_\_\_

29. Overall would you say 'TOP 5' is an effective strategy in managing residents 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 resident's carer in order to identify helpful hints & strategies that can be used to lessen the anxiety of residents and carers and gain a better understanding of how the 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 residents 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 kept 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 Residential Aged Care Facility 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

LHD  
FACILITY  
LOGO

You have been asked to provide feedback about the TOP 5 initiative. Our staff will have approached you 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 patient/resident/client?

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 patient/resident/client?

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 patient 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 patient/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 patient/resident.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



LHD  
FACILITY  
LOGO

- |  | 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 patient.                              | <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 patient/resident benefited as a result. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
10. How satisfied were you with the overall process of transferring the patient/your loved one into the Residential Aged Care facility?
- Very dissatisfied ☐    Dissatisfied ☐    Unsure ☐    Satisfied ☐    Very satisfied ☐

**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.