

TOP 5 –Toolkit



Community Services

Integrating carer knowledge to improve care for
clients with dementia

Acknowledgements: TOP 5 is an initiative developed in the Central Coast Local Health District (CCLHD, NSW). The Clinical Excellence Commission has designed this toolkit 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

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 the 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 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 person 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 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 Home Care Standards developed by the Department of Health and Ageing include Standard 2 "Appropriate Access and Service Delivery" which provides the framework for active partnerships with health care providers and service users (and/or their representative), in the development of care/service plans based on individual needs.

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 community service, 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
- 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?

Members of your staff will be asked to provide carers of clients with dementia with a TOP 5 brochure (see Appendix C) and engage with them to obtain their TOP 5 tips to assist the team to communicate and manage the clients care.

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

A client may also be discharged from hospital with a TOP 5 form already in place.

The tips and subsequent strategies obtained from the carer or staff member should be recorded on the TOP 5 strategy form (see Appendix E). This TOP 5 information can be kept in the client's home, somewhere where it can be easily found and identified by the community worker, who can access this information and support the client's care.

A TOP 5 tag (see Appendix G) can be placed at the main entrance of the client's home, so community workers can easily identify a TOP 5 client. The location of the TOP 5 strategies is written on the back for community workers to locate.

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

Similarly, if an ambulance is required for the client, a copy of the TOP 5 strategies should 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 client is in their care.

Review of the process

It is important that each time TOP 5 is introduced into the care of a client, 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.

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:

- 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 N – Q.

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 community services

Appendix C – TOP 5 Brochure for Carers with clients utilising community services

Appendix D – TOP 5 Poster for use in the facility

Appendix E – TOP 5 Strategy Form

Appendix F – TOP 5 ID Tags

Appendix G – TOP 5 Tag Process

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 Lanyards for staff

EVALUATION TOOLS:

Appendix N – TOP 5 Pre-implementation Staff Survey Form

Appendix O – TOP 5 Post-implementation Staff Survey Form

Appendix P – TOP 5 Carer Information and Consent Form

Appendix Q – TOP 5 Carer Survey Form

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TOP 5 GUIDING PRINCIPLES

Partnership

The integration of carer knowledge will provide a person centred approach to the care of clients 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 clients 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 to personalise the care

Caring for all

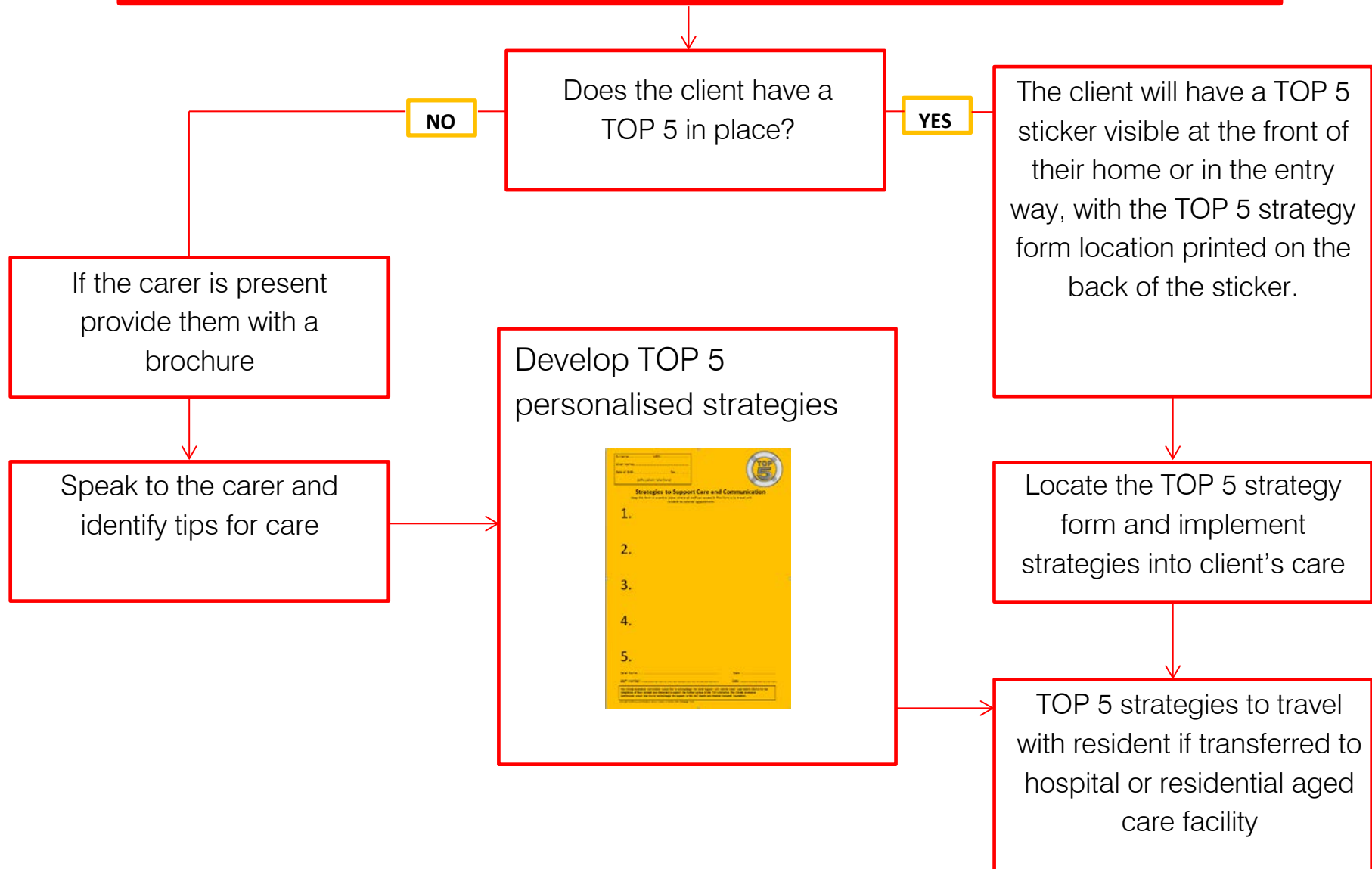
8. TOP 5 is one way to integrate carer knowledge into personalised care of a person with dementia. The intent is to lessen anxiety and de-escalate inappropriate behaviour thus providing a safer environment for staff and for clients who have cognitive impairment.
9. Every time TOP 5 is initiated it should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

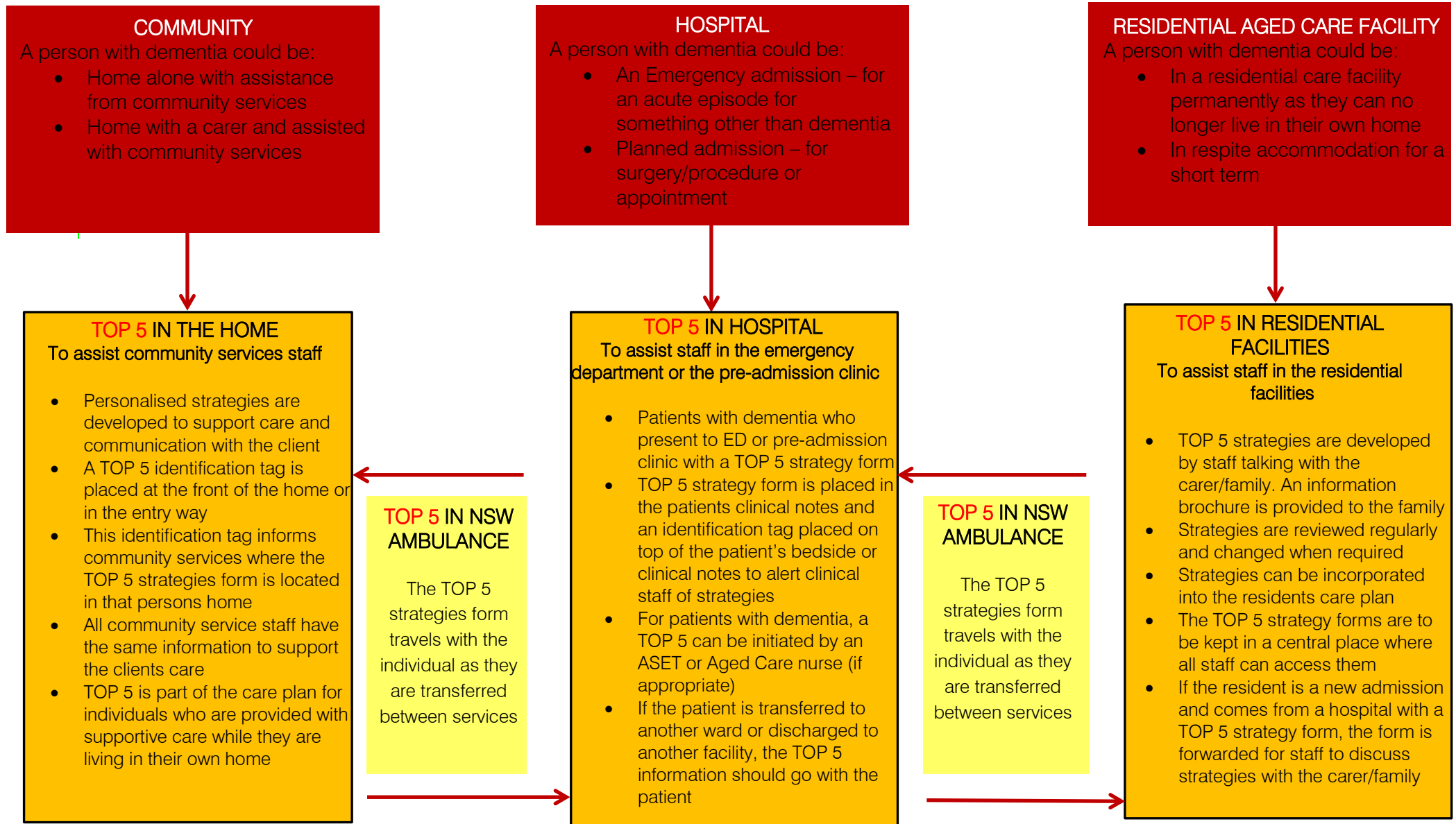
Clients with dementia who have been discharged home with community service support





TOP 5 PROGRAM

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



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

Clinical Excellence Commission - TOP 5 Phase 2 - Toolkit June 2014 Appendix B – TOP 5 Process



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 client.

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

COMMUNITY



TOP 5 helps to personalise care for clients 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 community workers know that Mum needs her fluffy rabbit named Pete with her at all times. If she is not holding Pete or if Pete is not within eyesight she can very easily become distressed or agitated"

Carer for mother



**This
information
is called**

This information (referred to as strategies) will be kept in the client's home, somewhere where it can be easily found and identified by the community worker, who will access this information and support the client care.

A TOP 5 tag can be placed at the main entrance of the client's home, so that community workers can easily identify a TOP 5 client. The location of the TOP 5 strategy form is written on the back of the tag for community workers to locate.

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

Similarly, if an ambulance transfer is required, a copy of the TOP 5 strategies can 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 client is in their care.

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 memory or thinking problems. The carer's knowledge of the client, especially in relation to communication and behaviour, can be the key to assisting community care workers when managing the care of the client, understanding their individual needs and providing reassurance in an unfamiliar environment.

What will happen?

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

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."

Carer for wife



TOP 5. Just a few easy steps....



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

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

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

5 STRATEGIES are then developed between the carer and staff to assist in keeping the person 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 client 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

The document will be kept in a safe place in the client's home.

Place a '**TOP 5 tag**' either at the front door or entry way in the client's home. The TOP 5 tag will have the exact location of the TOP 5 strategies form so that all staff that interact with the client will be aware that the, **strategies to support care of and communication with that client**, are available.



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.



<p>Persons Name.....</p> <p>TOP 5 Strategy Form location:</p> <p>.....</p> <p>.....</p> <p>Carer/Next of Kin</p> <p>Name.....</p> <p>Contact.....</p>	<p>Persons Name.....</p> <p>TOP 5 Strategy Form location:</p> <p>.....</p> <p>.....</p> <p>Carer/Next of Kin</p> <p>Name.....</p> <p>Contact.....</p>
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TOP 5: COMMUNITY SERVICES

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. 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 be asked to engage with carers to obtain their TOP 5 tips to assist the team to communicate and manage the client's care. Alternatively if staff members have a close relationship with a client and have come to know a client's personality over time, they also may be able to assist in developing the TOP 5 strategies for that client.

The tips and subsequent strategies obtained from the carer or staff member can be recorded on the TOP 5 strategy form. This information (also referred to as strategies) can be kept in the client's home, somewhere where it can be easily found and identified by the community worker, who will access this information and support the client's care.

A TOP 5 tag can be placed at the main entrance of the client's home, so community workers can easily identify a TOP 5 client. The location of the TOP 5 strategies is written on the back for community workers to locate.

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

Similarly, if an ambulance is required for the client, a copy of the TOP 5 strategies should 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 client is in their care.

Engaging with carers in this initiative will require the support of all staff in the organisation. You will be provided with information and additional skills, if required, to assist you to obtain the knowledge and use it to personalise the care of this group of clients

TOP 5 is a few easy steps

Talk to the Carer

The TOP 5 process 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 person 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

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 FOR A PERSON 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



The form is titled 'TOP 5 strategy form' and 'Strategies to Support Care and Communication'. It includes fields for 'Name', 'Date', 'Place of Birth', and 'GP/Referral Letter No.'. Below these are five numbered lines for strategies. At the bottom, there are fields for 'Care Name', 'Date', 'Staff Number', and 'Date'. A small circular logo with 'TOP 5' is in the top right corner. A disclaimer at the bottom states: 'The TOP 5 strategy form is a template and should be adapted to suit the needs of the patient. It is not a legal document and should not be used as a legal document. It is a template and should be adapted to suit the needs of the patient. It is not a legal document and should not be used as a legal document.'

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



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



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".



PRESENTATION NAME – MONTH YYYY
PRESENTATION NAME

"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

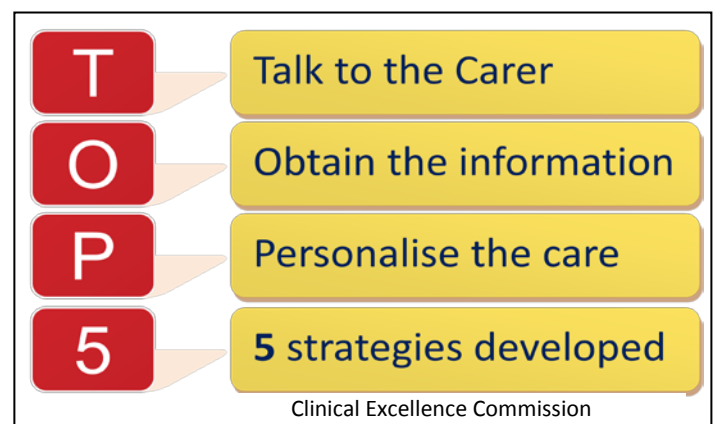
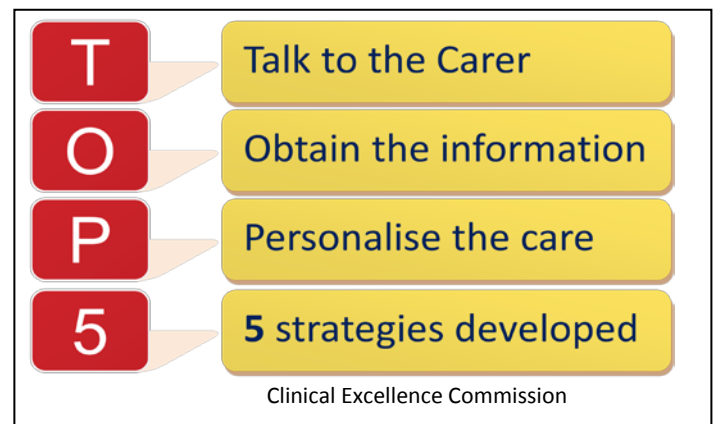
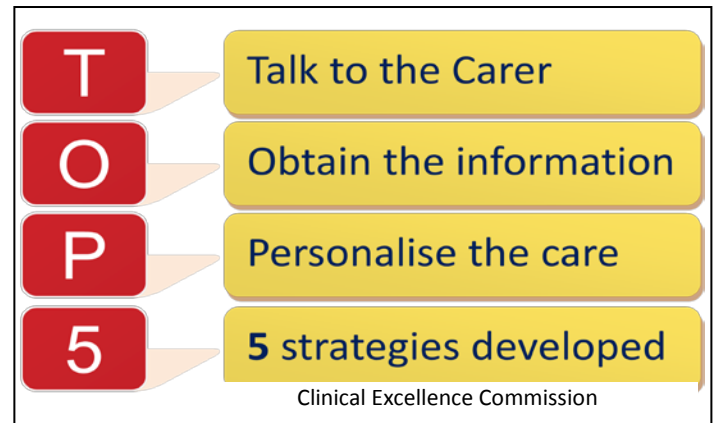
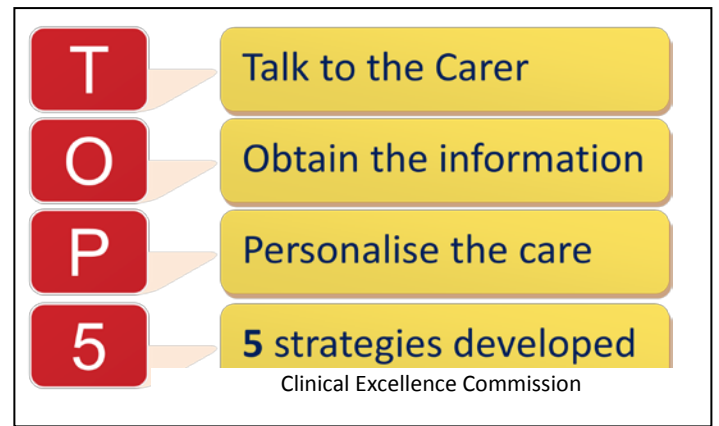


Communicating with people who have memory and thinking difficulties

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

TOP 5 is:

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



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
(Community Services)**

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 caring for an individual with dementia?

None/Little ☐ Some ☐ Average ☐ Extremely ☐

3. Are you satisfied that your service 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 the review/assessment/treatment of an individual with dementia?

None/Little ☐ Some ☐ Average ☐ Extremely ☐

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

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 SURVEY**
Conducted at 6 and 12 months
(Community Services)

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 caring for an individual with dementia?

None/Little ☐ Some ☐ Average ☐ Extremely ☐

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

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

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

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

4. Whilst caring for a client 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 with dementia, how would you transfer this information? (e.g. to a team member/other hospital)?

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

6. How important do you think it is to involve a carer in reviewing/assessing/treating a client 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 client/s?

Yes ☐

No ☐ → go to Question 17

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

Client ☐

Family/Carer ☐

Other

14. How easy was the 'TOP 5' process to implement and 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?

Yes ☐

No ☐

17. Was there a time where an individual was transferred from a facility/service to your service with a 'TOP 5' already in place?

Yes ☐

No ☐ → go to Question 22

18. Where was the individual transferred from?

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



19. How was the 'TOP 5' information typically received?

TOP 5 form ☐ Written ☐ Verbal ☐ Other _____

20. How successful was the transfer of this 'TOP 5' information to your service?

Poor ☐ Fair ☐ Good ☐ Very Good ☐

21. Please share an example of a 'successful TOP 5 strategy' that worked well for a patient with dementia. E.g. What was the strategy? How did it work?

22. Has an individual in your care with a 'TOP 5' in place been transferred to another facility?

Yes ☐

No ☐ → go to Question 27

23. Was the 'TOP 5' information passed on?

Yes ☐

No ☐

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

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

Other _____

25. Who was the information passed on to?

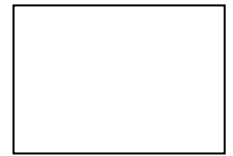
Doctor ☐ Nurse ☐ Allied health professionals ☐
Paramedic ☐ Carer ☐ Residential Aged Care Facility ☐ Don't know ☐

Other _____

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

Poor ☐ Fair ☐ Good ☐ Very Good ☐

27. What do you think of the TOP 5 program?



28. Overall would you say 'TOP 5' is an effective strategy to manage patients with dementia?

Yes ☐

No ☐

Unknown ☐

29. Have you heard any positive feedback from carers regarding TOP 5 (either when developing the strategies or after TOP 5 has been initiated for their loved one)?

Yes ☐

No ☐

N/A ☐

30. If yes what was the feedback?

31. Do you have any further comments?

**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 clients and carers and gain a better understanding of how the client 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 clients 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 Community Service 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 shortly after admission to gain valuable information from the knowledge and expertise you have in caring for the person who has become our client. 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 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 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 client 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 client.	<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 client.	<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 client. | <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 client 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.