BACKGROUND BITES

- Research evidence clearly demonstrates that an individualised approach to developing non-pharmacological approaches to specific responsive behaviour is consistently the most effective.

- Individualised approaches should include assessment for possible needs being communicated in responsive behaviour, including for relief of pain, fatigue, hunger, thirst, and boredom or overstimulation.

- The current consensus is that early and ongoing assessment of behaviour can lead to a more effective response from staff and a better outcome for the person with dementia and those around them. The reason for responsive behaviour should be assessed on a frequent, ongoing, and systematic basis.

- There is no magic bullet. Evidence shows that many non-pharmacological interventions generate good outcomes for people with dementia but outcomes vary from person to person, day to day, circumstance to circumstance.

- Life story work is a crucial part of understanding responsive behaviour and developing approaches to address the unmet needs of people with dementia.

- For any resident who exhibits an acute and fluctuating change in behaviour, an initial assessment for delirium should be made to rule out the presence of acute medical conditions.

WHY THE TERM RESPONSIVE BEHAVIOUR?

Behaviours often associated with dementia are referred to and thought of in many different ways, which can be confusing to aged care staff and family members. These behaviours have been referred to as:

- problematic,

- disturbing,

- difficult,

- inappropriate

- concerning, and

- challenging.

Such language actually reflects the perspective of the observer rather than that of the person with dementia.

"Responsive behaviours" is a term, preferred by persons with dementia, representing how their actions, words and gestures are a response, often intentional, that express something important about their personal, social or physical environment" (Alzheimer's Society Ontario).

This is a departure from the language previously used to talk about behaviour associated with dementia. The principles of understanding responsive behaviour are:

- All personal expressions (words, gestures, actions) have meaning.

- Personal expressions are an important means of communicating meanings, needs, concerns.

- Care partners require a multidimensional lens that seeks understanding of others' expressions.

THE SHIFT IN LANGUAGE IS AN IMPORTANT STEP IN SHIFTING THE FOCUS FROM THE CONDITION OF DEMENTIA TO THE PERSON AND THE ENVIRONMENT IN WHICH THEY EXPERIENCE LIFE.

The term responsive behaviour is more representative of the reality of the experiences of a person with dementia and those who care for them.

> As humans, our needs can vary greatly from day to day and what may meet those needs will vary depending on a range of circumstances. For people with dementia, the way in which they express unmet need through responsive behaviour may require equally as varied strategies to fulfil the need depending on the circumstances.

> It helps all of us grasp the reality that what supports a person with dementia one day, may not work the next day or even the next hour.

> It is a term that reminds us of the need to explore the reason why a strategy works for one person does and not consider it a failure if it does not work for another.

> It provides a basis for realising that an approach or strategy used by one care worker, may not be well received by the person with dementia when tried by a different care worker.

HOW TO START CHANGING THE LANGUAGE OF DEMENTIA CARE

Staff behaviour and language reflects respect and dignity for the personhood of all individuals. It is easy for us to fall into the habits of using terms and phrases in language and not realise the messages that are actually conveyed. There is very little emphasis placed on using better language in dementia care.

There is also little emphasis placed on being aware of the elements of both verbal and non-verbal communication.

For example, we can change a simple phrase like "I will help you to the toilet" go from being a gesture of support to a suggestion of inconvenience with just a sigh and change in intonation. Change the word 'help' to 'take' and it becomes a command. Neither demonstrates respect to the person with dementia.

As leaders and champions, it is worthwhile doing a quick exercise.

- Take time out and listen to the words that staff use when talking about their work with people with dementia.

- Examine the language used in care plans and other written notes.

- What does the language they use tell you?

- What language is used in your policies? Is it reflective of a person-centred approach? What message does it convey to staff about how the organisation thinks about people with dementia?

- What language is used in your public documentation? What message is conveyed to families, friends and the community about how the organisation thinks about people with dementia?

- And reflect on the language you use. Does it reflect the approach you are trying to promote and encourage in the facility?

There is most likely room for improvement as health and institutional language permeates dementia care regardless of the quality of care any given facility provides.

- Encourage staff to use positive language with each other and with people who have dementia.

- Negative, generalised labels for people with dementia should be totally eliminated from the vocabulary of staff, signage, and all documentation, including care plans. Examples include "feeder," "wanderer," "toileter," "screamer", "agitated," "difficult," "behavioural," "unmanageable," "redirect".

- Encourage the use of more positive, and more specifically, descriptive language is used to refer to people with dementia, e.g., "Person who needs help eating," rather than "feeder" "energetic and exploratory," rather than "restless and wandering" "needs help in the bathroom" rather than "needs toileting".

- Instead of labelling person with dementia as "agitated," in notes and care plans - describe the situation and what was done, e.g., "Person is talking loudly about his wife and pacing in his room - so I asked him to tell me about his wife."

It is likely that eyes will roll, eyebrows will raise and there will be murmurings of "political correctness gone mad". But if communication is clear about why using language a particular way is so important, staff will begin to see the value of it. The significance of this becomes clear in a later discussion of care plans as a form of communication.

When you get staff thinking about the language they use – it raises awareness and can have a knock-on effect to them thinking about other aspects of their engagement and interactions with residents and each other. But keep in mind – it is not just the language that staff use which is likely in need of revising.

Language lays the groundwork for meeting the needs of people with dementia expressed as responsive behaviour, the principles of which are (Dupuis, Wiersma, & Loiselle, 2008):

- a focus on understanding the meaning of personal expressions (words, gestures, actions).

- understanding the layered nature of personal expressions including at:
  - the individual/personal level (subjective experience of the physical body, cognition, emotional experiences, spirituality, and cultural beliefs),
  - the experience of the social environmental (the nature of caring and interpersonal relationships and broader cultural issues such as organizational policies and practices), and

  - the experience of the broader physical environmental (built environment, temperature, lighting).

- developing skills in active listening, being truly present, and using alternative ways to communicate.

- being open, non-judgmental, and compassionate.

DEVELOPING, COLLECTING AND SHARING INFORMATION AND IDEAS

In any given day in a long term care facility, hundreds of pieces of information are collected in various ways. There are many reasons for collecting and documenting information, but it is likely that equally as much information is not documented and, if we are being honest – to what extent a great deal of that information, documented or undocumented, is used in appropriately supporting people with dementia is questionable. Information is of no value if we do not use it successfully.

So while effective communication is essential to person-centred dementia care and in particular, to meeting the needs of a resident as expressed in responsive behaviour, how we use the information is even more important.

LIFE STORY WORK

In recent years, the importance of life stories or social history has been identified and it is now considered a fundamental component of the information collected about a resident.

The value of having this personalised information is absolutely critical to the delivery of person-centred care to support staff to:

> understand the meaning behind what people say;

> understand unmet need communicated by behaviour;

> reinforce the resident's identity and

> facilitate interaction and relationships.

However, there are some issues with life story work in RAC facilities:

- Life stories collected are often comprised of superficial information collected on admission giving the impression that life stopped upon entry into long term care. The value of the information diminishes over time as their experiences of the facility change the nature of the resident's lifestyle and preferences.

- Life stories are collected within the context of "a project" giving them status as something that has been completed and therefore after initial interest, likely to remain unvisited and unused.

- Information from life stories is not regularly utilised in care plans or is used in a limited capacity in every day care in inappropriate ways.

- Staff, residents, family and friends are often not afforded the opportunity to add to the life story or to read life stories on an ongoing basis.

There are many ways to develop life stories and to maintain them in a useful way. It is important to convey to staff that 'life story work' is not the sole domain of leisure/lifestyle/activity staff.

Find ways to involve staff in both development and use of information in life stories. For example, some facilities find assigning a specific room to a staff member and making them responsible for collecting a range of information about the resident in that room that will feed into the life story is a useful way to maintain involvement in life story work.

Similarly, having staff highlight information from resident life stories that they have found important in generating positive outcomes during care routines will help in keeping staff involved in life story work.

There are existing templates and tools for collecting information. With the development in digital technology, people are able to record digital stories and utilise the internet to support life story work.

The way in which the information is recorded is of lesser importance than the activity and outcome of doing it with the resident (and their family) and having the additional unique information about the individual.

More information, including links to Life Story templates and other ideas for engaging staff in life story work as part of their everyday work routines is available on the Dementia Dynamics™ website www.dementiadynamics.com.au.

Life stories and lifestyle preferences and wishes are extremely important for understanding responsive behaviour. Everyone should be responsible for contributing to and using life stories. As a form of communication, life story work plays an important role in meeting the needs of people with dementia but its value lies in the way the information about a resident it is utilised.

Champions should consider how they can:

- Review current system of collecting life stories

- Identify any issues with the quality of existing life stories

- Determine the extent to which life story and lifestyle information is used in care plans

- Determine the extent to which staff use life story and lifestyle information in meeting the needs expressed through responsive behaviour.

CARE PLANS AS COMMUNICATION

Care plans exist in every RAC facility but the extent to which they promote or enable person-centred dementia care can vary significantly. Many appear to inhibit staff from being person-centred. Care plans are supposed to guide the care provided but a number of common issues have been identified:

- In some facilities, care plans are so generalised that if you remove the residents names from care plans, it could be very difficult to find points of differentiation to identify the care plan with a particular resident.

- Some plans are focused on 'problems' or 'issues' and therefore perpetuate the negative aspects of the condition or the person, with little or no mention of strengths, retained abilities or potential.

- The template itself inhibits person-centred care with headings such as 'Identified Problems" or "Personal Care Issues".

This is not an exhaustive list of issues but is meant to point to how easy it is for such important documentation to promote poor communication which in turn, impacts significantly on its very purpose. Think about the previous discussion about the use of language. Consider the following two entries about personal care.

PERSONAL CARE ISSUES	PERSONAL CARE NEEDS
Gary can't brush his teeth by himself.	Put toothpaste on the toothbrush for Gary and hand it to him – he can then brush his own teeth.

Framed as an 'issue', the vague statement about Gary's inability to brush his teeth leaves it open to interpretation about what course of action is appropriate. Take a moment to consider how this could very easily lead to a situation from which responsive behaviour is the outcome.

Framed as a 'need' with a clear statement about what action is required to support Gary, the focus is on his remaining ability to brush his teeth independently. It is a clear communication to all staff about how to support Gary and meet this personal care need.

Leaders and Champions have a role to play in ensuring that care plan structure and use supports person-centred dementia care and provides clear information that will enable staff to meet the needs of residents with dementia.

> **Audit care plans**
> Champions will find a Care Plan Checklist provided in this manual which may be useful to audit care plans.

> **Revise and restructure**
> Based on the audit, determine whether the care plan structure is supporting staff to be person-centred in care delivery. Use your champions group to develop a better structured care plan and involve staff in decision-making about any changes. If you do introduce a new care plan structure, be sure to provide training so staff know what information is most useful and required, how it will best serve their needs in caring and meeting the needs of residents.

> **Ongoing monitoring**
> Consider the care plan a dynamic document and monitor entries (or lack thereof) and potential changes required so that it remains current and valid and not just documentation to meet accreditation requirements.

If staff are not using it – explore the reasons for this. If time is an issue (which is frequently the case) consider whether a summary sheet will be useful for everyday work practice but ensure that all staff do get the time to read the whole care plan.

SUPPORTING STAFF TO MEET THE NEEDS EXPRESSED IN RESPONSIVE BEHAVIOUR

Responsive behaviour is most commonly identified by staff working in RAC facilities as the single most challenging aspect of their work. It is important for leaders and champions to empathise and support staff through their everyday experiences of caring for people with dementia. Staff need the same level of respect, dignity and validation that we expect them to afford residents with dementia.

HELPING STAFF RECOGNISE AND ADDRESS RESPONSIVE BEHAVIOUR AS AN UNMET NEEDS
Helping staff recognise responsive behaviour and then consider and explore ways to address it begins with putting it into context in the workplace. Pharmacological interventions can be useful in some circumstances, but they should only be used as a last resort.

The Dementia Dynamics™ Toolkit focuses on non-pharmacological interventions for responsive behaviour. While education such as that contained in the Dementia Dynamics™ eLearning DVD provides a good foundation, ongoing learning through experience in everyday care practice will help staff build capacity.

The term responsive behaviour reminds us that there is no magic bullet. Champions have a role to play in:

- Fostering a mind set of "let's try this and see what happens".

- Encouraging staff to consider multiple approaches for any given responsive behaviour.

- Reminding staff that they should work on the basis of "different strokes for different folks" and that they are 'people of influence' in the life of people with dementia in their care.

Champions can support staff by giving them some straightforward, clear strategies to start them off – building on the learning from the DVD.

- Reminders of simple strategies can be put on a poster *(see example on following page).*

- Encourage staff to create their own "novel methods/approaches" for meeting a person's needs and share with others in different forums, including communication in written documentation such as the care plan.

- Select a key message(s) from the POP DVD and use it to generate discussion about a specific area of practice or to prompt discussion following an incident or practice issue.

- Use the DAPIR diagram as a poster to remind staff of the process.

Staff completing the Dementia Dynamics™ eLearning DVD will have learned about needs-based problem solving, so the DAPIR, one of the many tools provided with this toolkit, provides Champions with a familiar process for staff to work through and discuss the underlying reasons for responsive behaviour.

Learning circles may also be a useful tool to provide workplace learning opportunities that are practice-based. They are a specific forum created to facilitate communication:

- A group of staff that particularly includes those at the level of resident care, are brought together when decisions affecting resident care are being made.

- Each person is purposely provided the opportunity to contribute.

- It is useful to have the results of relevant assessments available such as information from the PANSiS or EAT tools.

Learning circles can be used regularly as part of the work routine and/or opportunistically as required. It is a particularly good forum for discussing specific responsive behaviour. It is a powerful tool to help teams make decisions and create solutions.

The inclusion of personal care assistants (PCAs) in a range of activities such as learning circles, resident case conferences and similar forums is often met with resistance.

However, research shows that their inclusion leads to stronger functional outcomes and increased resident and family satisfaction. If concerns are raised about the quantity (too much) or inappropriate information being provided by PCAs, champions can provide some basic training so that PCAs have a better understanding of:

- what to expect,

- what information is important, and

- how best to convey the voice and wishes of the resident.

EVERYDAY STRATEGIES TO ADDRESS RESPONSIVE BEHAVIOUR

Providing your undivided attention

Validate the emotions of the individual

Unconditional positive regard

Redirect the individual in a meaningful way

Sometimes doing nothing is a plan

KEY MESSAGES

★ The term responsive behaviour is more representative of the reality of the experiences of a person with dementia and those who care for them.

★ The language we use reflects our attitudes and can influence the actions of those around us. Language in communication needs to reflect person-centred principles and inform staff in a way that specifically guides their care actions to meet the needs of people with dementia as expressed through responsive behaviour.

★ Life Story Work is essential to understanding responsive behaviour. Life Story documents must be dynamic and should include past and present. It requires ongoing updating to include life experiences in the RAC facility.

★ The Dementia Dynamics™ Toolkit provides a range of tools that will assist staff to put the knowledge they acquired from completing the eLearning DVD into practice to address responsive behaviour.

★ The extent to which care plans are implemented and reviewed will depend on the value and importance given to this process in the work place.

★ Leaders, champions and all staff should regularly login to the Dementia Dynamics™ support website to access additional information, tools and resources.