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Guidelines on Behavioural and Psychological Issues associated with dementias		

Behavioural And Psychological issues associated with dementia	
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Please read in conjunction with

Guidelines on communication

Guidelines on communicating with people with dementia.

Policy on violence and Policy on verbal de-escalation

Guidelines on dealing with people from a medical perspective

Guidelines on working with people with dementia

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Guidelines on BEHAVIOURAL AND PSYCHOLOGICAL ISSUES WHEN WORKING WITH PEOPLE WITH DEMENTIA.

1.0.What is Dementia?

Dementia is not a disease, but rather an umbrella term for a variety of symptoms that may accompany or indicate certain diseases or conditions. Today over 60 different conditions are known to cause dementia symptoms.

After a dementia diagnosis, the focus is often only on the person's symptoms and behaviour rather than on his or her needs. It can seem that there is not much that can be done, which makes it very hard to maintain a positive attitude. However, if you shift your focus and energy to the person's strengths and remaining abilities, it helps you keep a positive attitude and enables you to encourage and inspire improvement, joy, hope, and wellbeing in those you support .

1.1.Person-centred care

This guideline offers best-practice advice on the care of people with dementia and on support for their carers. There is broad consensus that the principles of person-centred care underpin good practice in the field of dementia care and they are reflected in many of the recommendations made in the guideline. The principles assert:

- the human value of people with dementia, regardless of age or cognitive impairment, and those who care for them
- the individuality of people with dementia, with their unique personality and life experiences among the influences on their response to the dementia
- the importance of the perspective of the person with dementia
- the importance of relationships and interactions with others to the person with dementia, and their potential for promoting well-being.

The fourth principle emphasises the imperative in dementia care to consider the needs of

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carers, whether family and friends or paid care-workers, and to consider ways of supporting and enhancing their input to the person with dementia.

- 1.2. Symptoms and Stages of Dementia

Dementia symptoms are often grouped in ‘stages’ – here we refer to 4 different stages. These stages should only serve as guides though as each person responds differently to their particular symptoms, and stages can fluctuate and overlap. A person may show symptoms common to the early stage one minute and those common to middle or late stage the next. These variations can be very much dependent on whether the person is experiencing an underlying physical condition or the lack of genuine respect and appreciation.

Though a person may appear muddled one particular day – or in the morning or afternoon – this doesn’t mean that the person is ‘locked’ at that point or has moved on to the next stage. It only means that this is where he or she is at that particular moment and this may change and the person may revert to being quite clear again.

The definitions we use here for the 4 stages are expressed from the point of view of social psychology; and are different from those of the medical model, which focuses mainly on the deterioration occurring in the brain. (Note: Research has shown that there is little correlation between the severity of brain damage and how it actually affects a person with dementia.)

We can all be forgetful at times. Who hasn’t gone to another room and arrived to wonder what they were doing there? Who hasn’t forgotten what day it is momentarily, especially when on holidays? Who hasn’t misplaced their car keys on occasions? The difference for the person with dementia is that he or she may find the keys but not know what to do with them.

In the **first stage**, people with dementia begin to experience that something is not right – *‘The old memory is playing up.’* They may feel embarrassed or frightened when they recognize changes in their memory or thinking. Family and friends begin to question and comment on the changes and forgetfulness. The person is likely to fight to keep up the façade of ‘normality’ and being in control.

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They might do things, such as making up a little story to fill the memory gap of someone or something they can't remember. Professionals label this gap filling as 'confabulation'. However, this 'story' telling or gap filling does not mean that the person is telling a lie. It is actually a creative, self-defence mechanism that helps the person to keep up the façade. It will help supportive partners and 'carers' to understand if they can imagine it in this way too.

The person may express anger or annoyance to direct questions requiring memory or thinking skills. A seemingly simple question, such as: 'Where were you born?' may elicit a snappy, 'That's none of your business!'

Also, the person might blame others for his or her memory lapses.

Lydia cannot find her glasses. She asks the care assistant, 'Have you seen my glasses?' Eric recalls seeing them earlier in the bedroom, and says, 'Have a look on the bedside table. I think you put them there.' Lydia is not going to admit that she might have put the glasses there herself and forgotten; so she says, 'Well, you must have put them there, because I didn't.'

This type of response is easy to take as an accusation, but it is not. It is simply the person fighting to hold on to a small piece of control and to keep up the façade.

Sometimes the person in this first stage can cause considerable stress to family and friends, when the person may want to check and recheck everything. Paul may ask, 'Is it today that my son is coming?' 'What is the time?' 'Is today Monday?' He checks again and again, until patience frays and frustration builds. It is important to remember that Paul is not doing this to annoy you; he is simply trying to reassure himself that he is in control.

People in this early stage seem to use every opportunity to exercise the control they feel they are losing.

When Mary says, 'Mum, we are going out at 3 o'clock,' and they have not left by 10 past 3, Mum may pull her up. 'You said we were leaving at 3, and it's 10 past 3!'

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Mum is not trying to challenge Mary; she is simply trying to show that she remembers that they had a different arrangement.

In this **first stage**, people with dementia generally use much the same language as most people do. They might forget a word, a phrase or a memory and then create a little story to fill the memory gap. Sometimes they may also appear vague in the way they communicate.

Instead of Stan saying, 'Please give me the cup,' he forgets the word cup and (while pointing at it) might say, 'Please give me that one.'

He might use vague phrases such as, 'Something has happened', or, 'Something is not right.'

These are just two examples of the wonderful way people with dementia compensate for missing memories.

Or they may try to get us to create multiple-choice questions so they only have to answer one of them, and, in that way, we jog their memory too. For example you might ask Stan, *'Where have you been?'* his response might be, *'Oh, you know where.'*

Note: It is far easier for people with dementia to recognise situations that are described to them rather than to remember something out-of-the-blue.

In the **second stage**, people with dementia are far more relaxed and inclined to give in and let go. They may start to withdraw and appear to become preoccupied with the past, thinking back to happy times, restoring old memories and sometimes living in that time and reality. Their way of communicating may change too. Sentence construction may not be as clear. They might start a sentence, and it make perfect sense; but then it becomes muddled in the middle and ends as 'gobbledegook', which is hard to understand.

If they can't remember a word, they might create one. Often the words will be familiar, only now put together in an innovative way creating a poetic new word or phrase. Here is a great personal example of how this can occur.

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One day we were out driving. Suddenly, Mum pointed out of the window and said, 'Look at that beautiful water nest.' I looked across at the pond in the paddock and thought, 'What is she talking about?' Then I realised. Mum couldn't remember the word for pond, so, instead, she'd said, 'water nest.' A far more beautiful word picture than pond!

Another time, she said, 'I can't find my rain stick'. I did have to wonder for a moment about this rain stick? Of course, Mum meant her umbrella.

Once we work out the intended meaning, it can seem so obvious.

People who have dementia develop their own wonderful language. Each person is unique and so will develop an individual style of language that those closest to them will learn to understand. A close family member may even get to a point where he or she doesn't even think of it as different.

In the **second stage**, the person may start to mix up relationships and generations, such as Emily believing her son to be her deceased husband, or Ray believing his niece is his sister.

The person may start to address you by a different name. Just because you are addressed in this way for a short time does not mean it will last forever. It may only be that the person is preoccupied, for the moment, in thinking about Mum or Dad. So, when you appear, you may temporarily become Mum or Dad.

In this stage, the person may still be able to do many things, but might become sidetracked when starting on something new.

Evelyn pulls out a drawer to put something away. Once the drawer is open, she is inspired by what she sees inside and forgets what she came to do. Instead, she begins to empty the contents.

John may begin to set the table using the correct movements; but once he spreads out the tablecloth, he forgets what he is doing. Suddenly, re-inspired, he begins to fold the cloth up again and puts it away.

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Some of these actions can be frustrating, but they are easier to understand when we know that the person is not deliberately trying to frustrate or irritate; it is simply that he or she sets out to do the one thing, and then gets distracted.

In the **third stage**, people with dementia start to withdraw even further into the past and become so preoccupied with their memories that they ‘live’ almost entirely in that time and reality.

They may also start to wander. When this happens, it is important to know that there is usually a valid reason. Either the person is looking for something or someone, or is trying to prevent boredom.

The person may also start expressing needs, wants and feelings increasingly through body language – using gestures and actions. For example: Some may sit picking minute fluff-balls off clothing, wringing their hands, or appear to be kneading dough or mending clothes. These are ways of going back into the past and recreating a time when they felt needed, useful and special. Often these positive experiences are missing for them in this reality. These movements do have purpose, even if they might seem strange to us.

Language, at this stage, may consist mainly of one-syllable words, such as ‘Yes’ and ‘No’, interspersed with only a key word. This key word might be a noun or a verb, but is always something that has particular meaning and that we can take note of to help us understand what is being talked about.

We can maintain communication with people who have dementia in all stages. The person may become incontinent in the third stage, but, remember, this may not necessarily happen.

In the **fourth stage**, people with dementia may completely shut out the outside world. They might sit in a chair or lie in bed staring straight into thin air, or they might have their eyes closed. They may not respond when someone walks into the room or speaks to them.

Today, we know that the person at this stage still hears and experiences through touch, and it is extremely important that we continue to talk with them and still make physical contact.

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1.3. How to communicate to someone who cannot speak.

Communicating with someone who can no longer speak in words or sentences can sometimes seem like a tough task.

The good news

People with dementia still do communicate, even if they can no longer use words or sentences. Today we know that most people with dementia retain the ability to communicate, at least in one-syllable words, such as *yes* or *no*.

The only exceptions to this rule are people in the final stage of dementia or who have suffered a stroke or similar condition that may have affected their “speech circuitry”.

A *Yes* or *No* answer can be given in 3 different ways by:

1. **Saying** the words out loud.
2. **Shaking or nodding the head** to indicate a response.
3. **Using facial expressions** e.g. looking up and making eye contact; smiling or looking down for a *Yes*, or: looking straight into space or giving no reaction at all for a *No*.

Research has shown that words are not our only means of communication. We use three components when communicating a message:

1. **Words** – which make up 7%
2. **Tone of voice** – which makes up 38% and

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3. **Body language** – which makes up 55%

This means that **93%** of our communication is non-verbal, and it is in our tone of voice and body language that meaning is conveyed. We can say a word or sentence, but give it a completely opposite meaning through our tone of voice and the look on our face. The reality is that people with dementia who have 'lost' their speech (only 7% of their communication) still retain the ability to share all their emotions by communicating non-verbally in actions and sounds.

A good listener

The objective of communicating with someone who can't put words or sentences together is to help the person make sense of what is going on inside his or her mind and to express it.

The first essential to being a good listener is to listen with your heart; to listen with feeling. Ask yourself:

- What is the person attempting to communicate?
- What is the need that is not fulfilled?

Use your body language to show the person you are listening – really listening. Think of yourself as a "servant friend" and to do this:

- Bend or kneel down so that you are at the same eye level.
- Look the person in the eyes in a warm, open and welcoming way.
- Bend forward to show you are there 100%.
- Place your hand on their hand, arm or knee or around their shoulder to give comfort and to show that you genuinely care.

When you use touch you need to remember to be completely honest with yourself.

Acknowledge your own and the other person's boundaries.

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Intuition

Use your intuition as a guide to help you guess what the person is attempting to communicate.

Intuition is our lightning fast ability to take in information and process it in relation to anything we have learned previously or experienced. It gives us our initial response to a question. To do this incredibly fast processing, our intuition makes use of both hemispheres of the brain.

Your logical, rational thinking then sets in with its response. Often you may experience this as a dialogue inside your head between the two hemispheres where logic rational thinking will try and convince you why *its* answer is correct and why your intuitive answer is not. Interestingly, logical rational thinking only makes use of half of your brain capacity. If you have ever played Trivial Pursuit you may have had the experience where, as soon as you heard the question, you instantly had the answer – your intuitive response. Then, before you actually said it, another thought came into your mind – your logical rational response; a thought that challenged your initial intuitive answer.

As you have most likely been taught to listen to your logical rational responses you chose this answer above the intuitive one, only to find that it was incorrect. Your first answer – the intuitive one – was the right one.

This example shows how smart and quick your intuition works for you. It is why you are bound to make the best and most precise guesses when you allow yourself to listen to that lightning fast first thought that comes to mind. Hold on to that thought – to that guess.

Questions to ask

Once we have guessed what the person is attempting to communicate, we need to acknowledge the need or feeling that is being expressed; then check this “guessed” need or feeling with the person.

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- Check by asking the kind of questions that seek only a Yes or No answer. If the person is expressing what you have interpreted as sadness, you could say:
- You **look** sad. *Is that how you feel?*
- You **sound** sad. *Is that how you feel?*
- I **sense** you are sad. *Is that how you are feeling?*

Here are some other examples using the same principles. This time you repeat **what says or does**, then check your “guessed” interpretation.

- When you are looking for your mum – are you looking for love? (In this case love is the feeling you have intuitively guessed.)
- When you say you want to go home – are you feeling lonely? (In this case loneliness is the feeling you have intuitively guessed.)
- When you are tapping your fingers hard on the armrest – are you feeling angry? (In this case anger is the feeling you have intuitively guessed.)

The lesson here is that we need to ask the question: **Are you...?** We can always use this in some way because it only seeks a **Yes** or **No** answer, which are the easiest possible responses for a person with dementia to give.

A huge bonus to this technique is that it has no negative side effects. The worst thing that can happen is that your guess is not correct and then all you need to do is to ask another question. Simple!

Once you have discovered the need or feeling the person is expressing, it's then a matter of finding a way to meet that need.

Your role

Think of the person with dementia as forming a close partnership with you so that **together** you find the answer to what they are attempting to communicate. You can't do it on your own because you are relying on the directions given by them. Whenever people

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with dementia say, Yes it means you are on the right track; when they say, No you are at a dead end and need to choose a new path to explore. They can't do it on their own because they rely on you to articulate their feelings and needs.

Be a good communicator In communicating with a person with dementia, it is always the responsibility of the communicator to ensure the message gets through. So no more, '*I told you so!*' or '*I've already told you twice!*' or '*Haven't you been listening properly?*'

Instead, invest the time and effort to ensure the other person truly understands that you will partner them in the process of communicating.

To do this:

- Use the same body language techniques that you use to be a good listener.
- Make sure you have eye contact before you begin to talk.
- Use short simple sentences.
- Use your own body language to be expressive and to underline your message.
- Offer only two choices at a time.
- Pace yourself to match the person's pace.

Contrary to myths, people with dementia **do know** how they feel and what their needs are. They simply express them differently, and it is our obligation to tune into their special ways of sharing their needs and feelings.

- **1.4. Symbolic Language.**

The idea that people with dementia communicate via symbols makes sense. This belief is important and integral in allowing us to tap into the meanings behind their special language of spoken and gestured symbols. By focusing on the messages conveyed through rich symbolism, we can move towards a deeper understanding of the individual person.

"Symbols are profound expressions of our inner psychological forces." They enrich our minds and imaginations. They appear in every conceivable form: pictures, metaphors, sounds, gestures, odours, myths and personifications and draw from all sources, material

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and non-material, for their inspiration. Symbols arouse our curiosity as they imply something vague, hidden and unknown to us.

Carl Jung

Although symbols are often dismissed by our Western rationalism, they have occurred in all cultures across the ages. We owe much of the knowledge we have today on the importance of symbols in our psychological life to the pioneering work of **Carl Gustav Jung** (1875 – 1961), who was a remarkable Swiss psychologist and psychotherapist. Jung saw symbols as vital clues to our emotional, psychological and spiritual problems and also as indicators of progress to recovery.

Sigmund Freud also attached great importance to the use of symbols in understanding the human mind, but took them to mainly represent repressed sexuality. For example: anything erect, that can be erected, or penetrate, is regarded in Freudian theory as a symbol of the male sex organ. To **Jung**, symbols of male and female sexuality were simply expressions of deeper, creative psychic forces.

Naomi Feil

In 1982 Naomi Feil published her first book: *Validation – The Feil Method*. She introduced the idea that people with dementia may communicate through a language of symbols, using spoken words, props or movements. She created two lists of symbols. One representing objects: such as jewellery or a handbag etc; the other representing body parts: such as a hand, or movements like rocking etc. Her interpretation of symbols appears to be based on a mixture of Freud and Jung – leaning more towards Freud, as many of her suggestions for interpretations are of a sexual nature.

Contrary to Naomi Feil, Verity (2010) interpretations of symbols tend to be mostly inspired by Jung as she I, too, looks for the deeper meaning behind the concrete symbol. Her work is also influenced by techniques learned from NLP (Neuro Linguistic Programming) that tap into the unconscious mind.

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Spoken Symbols

The following story illustrates a real experience using symbolic language as the basis for interpretation.

Lorna had dementia and lived in a residential care facility. Every morning, when her breakfast was placed in front of her, she would call out in a loud, accusing voice: ***My porridge is poisoned!***

The cook had tried everything; she avoided adding even a pinch of salt to Lorna's porridge. She tried adding sugar, but nothing seemed to help and Lorna kept repeating her accusation.

When a person with dementia is adamant about something that does not appear real to us, and that person does not have a psychiatric illness, it is usually a sign that they are communicating in deeply, symbolic language.

In the traditional medical world of psychiatry, Lorna's statements would be labelled hallucinatory or delusional and lead to her being medicated, resulting in the disrespectful side effects of withdrawal; immobility and incontinence to name only two.

Since it was known that Lorna's porridge had not been poisoned, and she did not have a psychiatric illness, her adamant statement was actually an extremely clever and symbolic way of telling those looking after her that not only were her emotional and spiritual needs not being met, but the way she was being treated was destroying her spirit.

We refer to spirit here as the driving force that lies at the core of our being—the inner light that gives passion, meaning and purpose to our lives. When our spirit is broken—what is then left? Only an empty shell, longing to die! Could it be that when Lorna so strongly voiced her statement, she was fighting to preserve what was left of her essence? 7 Step Symbol Solver Please refer to Poster. The following is a 7 step model designed to elicit the

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symbolic meaning behind a statement such as: ***My porridge is poisoned!*** Always work from the assumption that a statement, such as Lorna's, shows the state of the person's spirit. It represents a **social, emotional or spiritual** need that is not being met either now or in the past. Also understand that the person is definitely experiencing a need, but does not know how to express it exactly in words, and therefore conveys the meaning deeply embedded in symbolic language instead.

Step 1. Pick out every noun in the original statement, such as: *Porridge*, then every verb, in this case, *Poisoning*.

Step 2. Ask yourself the following question for each noun: ***What does this represent?*** Starting with the noun *Porridge*: What does *Porridge* represent? *Porridge* is food—meaning nourishment, which can also represent **emotional** and/or **spiritual** *Nourishment*.

Step 3. Repeat the original symbolic statement but, this time, replace *Porridge* with *Nourishment*. *My Nourishment is poisoned!* This no longer makes sense to your logic and rational thinking, so allow your intuition to take over. **What could this mean?** If no answer comes to you—that is absolutely OK. Just leave it and move on to the next step.

Step 4. Now to the verb, *Poison*. Again, ask yourself the following question: **What does Poison represent?** *Poison* destroys *life*.

Step 5. Go back to the original symbolic statement and rephrase the entire sentence with your new knowledge about both nouns and verbs: My **emotional or spiritual** *nourishment* *is destroying my life*.

Step 6. Close your eyes and, with an open mind, consider what this new sentence could mean in relation to this particular person. The quality of Lorna's **emotional and spiritual** nourishment is now relying on the quality of the love and support she receives from those around her. Clearly what she is receiving is not fulfilling her emotional and spiritual needs. Could it be that Lorna has the wisdom to express her insight into the devastating effects the negative quality of her care is having on her whole being? It could not be said in a more powerful way!

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Step 7. Now it is time to check your assumption with the person. In a gentle, compassionate voice, which influences your whole being, ask, '*Lorna, are you feeling that the lack of emotional and spiritual support is destroying you?*' Or, '*Do you feel the quality of the care you are receiving is destroying you?*' Or, '*Do you feel our attitude is destroying you?*' Wait for her answer.

Helpful hints

1. You need to truly believe that the person's statement carries symbolic meaning of great importance and that you need to find this meaning in order to enrich the person's life.
2. Take one step at a time.
3. Use a good dictionary or thesaurus as support. (Looking up the different words may help you to find clearer and deeper meanings behind the words.)
4. Allow a day or two to pass for an idea or answer to emerge.
5. Discuss the statement with a colleague or family member to help find new insights and ideas.

The good news is that this approach has no negative side effects. The worst that can happen is that you may not find the right interpretation the first time around. All you need to do then is to give it another try.

1.5. Gestured Symbols

While the language of Spoken Symbols is often labelled as hallucinatory or delusional, the language of Gestured Symbols has not been labelled and seems to be met instead with only puzzled wonder. Gestured Symbols may be expressed using body movements (such as: caressing a closely curved arm - representing a baby) or through the addition of props (see example below). We can understand the language, once we discover the meaning behind the movement or prop.

At a presentation in Bundaberg, they were talking about symbolic language when one of the participants asked: 'What does it mean when one of our residents, Ivy, takes her dentures out every morning and places them between two slices of bread?'

By using the above 7 Step Symbol Solver and a combination of intuition and movement,

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mirroring Ivy's gestures, the idea evolved that the *dentures* could represent her *ability to talk or communicate*. The *bread* could again represent *food* → *nourishment*. The gesture of placing her *ability to talk or communicate* between the 2 pieces of *nourishment* could represent *suffocation*. In other words, does Ivy feel that the kind of *nourishment* she is receiving *suffocates* her *ability to talk or communicate*?

When this suggestion was offered to the participant, it was like enlightenment – the symbolic gesture suddenly made so much sense. Ivy had recently been moved from the hostel to the dementia unit, where she had no one to talk with, whereas, previously, she'd had many people in the hostel ever-ready for a chat.

The fact that Ivy was able to communicate her need to talk with people in Gestured Symbols inspired the staff to reverse their decision for her to live in the dementia unit. They would now ensure her return to the hostel and spend more time talking with her.

Mirroring of movement When you are working out what a symbolic gesture or movement may represent, it can be helpful to invest a few moments mirroring or experiencing this same gesture or movement for yourself. Find a quiet spot (you may have to wait until you are at home). Sit or stand just like the person with dementia. Close your eyes and mirror their gesture or movement. Allow yourself to **experience** the feeling. **What could this represent?** When you focus all of your attention on the **experience**, the idea is likely to come effortlessly. If you focus your attention only on the solution, you are less likely to find it.

Here is an example you can try. Sit quietly in a chair. Fold your arms in front of you and close your eyes. Now rock slowly backward and forward. Keep rocking until the movements take over. Allow yourself to experience: is it comfortable? Is it soothing? Keep rocking. What is it like? Could it be that when people with dementia sit rocking, it is not a symptom of dementia but rather a way of nurturing themselves in a world that lacks nurture, comfort and love? Physical needs Sometimes, what might appear to be a Gestured Symbol may, in fact, be a straightforward physical need that we miss because we have not tuned into the meaning **behind** the gesture. We need to be sure we don't overlook the obvious.

To illustrate this best, I will tell you about Clive. Everyone agreed that Clive was

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inoffensive, until, one day, he stopped by the nurses' station and, to everyone's surprise, placed his naked penis on top of the desk. His action was instantly labelled *inappropriate sexual behaviour*. However, one staff member did wonder if there was another reason. Yes! Clive was only trying to communicate his need to visit the bathroom. His need must have been misunderstood for quite some time for him to make such a drastic gesture, but it reinforces my belief that there is always a meaningful reason behind the words and actions of a person with dementia. Best attitude To become successful in finding the meaningful social, emotional or spiritual reason that lies behind symbolic language - whether spoken or gestured - you need to be fully present in the moment with the person who has dementia. You also need to:

- use empathy and compassion
- lift yourself away from concrete, logic, rational interpretations of words and gestures
- be open to your own intuitive thoughts of possibilities
- ask gentle, ever deepening questions
- be patient.
-
- **Universal symbols** The above examples of Spoken and Gestured Symbols represent unique, individual experiences. However, there are some words, gestures and objects that hold universal significance. Their images and like-meanings can be found across all cultures and centuries. Some of these universal symbols are:
 - **Food** As seen in the examples above, any word or object akin to food relates to Nourishment, either emotional or spiritual.
 - **Folding and holding together**
 - Folding a napkin, handkerchief, piece of paper towel or anything that can be folded – usually being very exact and folding the item over and over again OR placing paper clips in precise order around the edge of a piece of paper, photo or other paper item OR winding elastic bands around and around a rolled up piece of paper or bundle of pens represents *compensation for loss of identity*. People with dementia appear able to compensate in the outside world for losses in their inner

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world. They fold themselves into place or hold themselves in place using paper clips or elastic bands.

- **Coins and keys** Coins and keys both represent *Worth*. Men, in particular, tend to find comfort in jiggling coins and keys in their pocket when they are a little uncomfortable. This action gives reassurance and strength.
- **Handbag** For many women, their handbag becomes a symbol of *Identity*. They tend to hold on to it for dear life and not let go. It doesn't seem to matter what is in the bag, the behaviour is the same.
- **Call to action** How much longer can we simply shrug our shoulders and ignore the persistent language and gestures of people with dementia, who so desperately seek our understanding? It is time to take notice and explore a new way of discovering the needs and meanings behind their deeply symbolic expression.

7 simple steps are all it takes.

- Here is a story which demonstrates how we can elicit meaning where once the words made no sense.
- Ranji was adamant that her neighbour was trying to kill her. She kept ringing the police, who had checked out the situation on several occasions only to find that Ranji was perfectly safe. Being a strong believer in the meaningful symbolism behind such strong statements of people with dementia, I intuitively tried to understand what might lie behind Ranji's fear that her neighbour was trying to kill her.
- Her fear of being killed seemed reasonably straight forward, in that, symbolically Ranji feared something inside her or parts of her were being destroyed or perhaps she even feared for her future. But what could the neighbour represent? I needed to look beyond the words and go one step further. I needed more information to discover what her neighbour represented.
- First, it was crucial to build Ranji's trust in me using body language, my whole person and all my energy. I compassionately asked Ranji to tell me about her neighbour, adding questions to gather more content. Gradually, she told me that the

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police had come and shot her neighbour 10 times! I couldn't help myself but responded that it sounded like her neighbour was superhuman! Ranji slowly bent forward and whispered: *Yes... he is the Devil!*

- Here was the clue and the turning point. Ranji was adamant about something that did not appear real to me and, therefore, I knew that the Devil must represent something deeply symbolic for her. *"The Devil is universally a symbol of evil. He is the opposite to what is considered good. His entire purpose is to deprive humans of the grace of God."*
- 1Ranji WAS ASKED if her fear that the devil was destroying her represented an inner fight between good and evil and if she was afraid that evil was going to win?
- The answer emerged over two longer sessions where Ranji told about her life. She had been brought up in a distant country with a very different culture and a strong belief in God. However, now in old age, she feared the fact that she had on a few occasions doubted God. The first time was when her daughter was raped and killed in front of her eyes; the second when her husband was taken away by soldiers never to be seen again.
- Knowing of Ranji's deep faith, SHE WAS asked: *"Do you fear that you are **not** going to go to heaven?"* Ranji's response was a very clear: **"Yes."** We may not be familiar with Ranji's religious persuasion, so she needed to be asked whether her God represented a gentle, forgiving God or a punishing God. She said her God was forgiving.
- Once we are assured that her God was forgiving, we then can ask if it would help to ease her pain and fear over having doubted God if she could see a representative from her religion to pass on forgiveness to her.
- She had tears in her eyes when she said: "Yes."
- A visit was arranged and, from that day on, Ranji never again accused her neighbour of trying to kill her and she remained living independently in her own home.
- Ranji's behaviour was a deeply symbolic manifestation of her deepest fear and not hallucinations or delusions linked to dementia as first thought.

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- Many older people no longer have the mental or physical energy to suppress deeply buried emotional turmoils and tragedies and these can often re-emerge late in life. This means that no matter how much background information we have on a person it may still not give us the necessary clues. Often these experiences represent 'skeletons in the closet', which no-one may have any knowledge of. However, by looking into the symbolism behind their words you can often elicit the real meanings behind much of their pain and behaviour.

1.6. Routines or Chores.

Routines vs. Rituals

In our everyday care of people with dementia, we often talk about the daily routines we have to carry out. We do not usually connect these with joy. More likely, we see these routines as chores; experiences we need to get over and done with as quickly as possible. The actual experience is not the focus.

Routines are regular, unvarying or mechanical procedures. No wonder we cringe when we hear the word routine and then tend to approach a routine job with little enthusiasm or excitement.

Rituals, on the other hand, are enriching ceremonies which:

~ lift the spirit and build trust

~ create familiarity and the joy of recognition

~ reduce insecurity and anxiety.

Creating ceremony means to transform the environment from the ordinary to the extraordinary with music, clothes, make-up, accessories, scents, lighting and other means.

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It is also about the way we conduct ourselves. There is a certain celebratory experience of ease and success. Creating Ritual is about the special way in which we perform an activity and the fact that we do it in the same way every time. Rituals build companionship.

People with dementia often experience separation, misunderstanding and alienation. One way of healing such suffering is through personalised and meaningful rituals.

Personalised, meaningful rituals

Developing and fine-tuning personalised, meaningful rituals is not about creating rituals where 'one size fits all'. Instead, there is a need for openness to the unique differences, preferences and possibilities that emerge through close contact with the individual. It is a process that evolves over time, starting with one or two small rituals and building on these, one by one.

Rituals are the little things we need to say and do, in the same way, every time, every day. What sets rituals apart from chores is our tone of voice and the way we add opportunities to boost self-esteem and make the person feel extra special. For example: When you add smell to a ritual - Give Eric the aftershave to hold and smell for himself, saying, *'Doesn't that smell fantastic?'* Then after you dab scent on him, with enthusiasm, repeat, *'Now you smell fantastic too.'* Once you receive positive feedback from Eric - confirming this ritual really works for him, you can then add it to the enriching rituals you use together every day.

By adding special phrases, words and unique touches - repeated every day - rituals turn the mundane into personalised, meaningful experiences. The bond and positive effects on all in your care will make these extra efforts so worthwhile and may actually even save you time.

The following morning rituals were created for people who have moderate to severe dementia and who are incontinent. They are meant as guides that you can pick from and adjust to the unique needs of your loved one, or your special residents, clients or patients.

Morning rituals

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The best way to begin a successful morning ritual is to greet the person with a beaming smile. Say that you'll open the curtains so the person can see the new day.

The person may or may not like you going into their cupboard or drawers, so we suggest that you assist the person straight onto the toilet. Once seated, you can help to remove any pads or disposable pants, while constantly reassuring that you are going to get some FRESH ones. We've found it works best to use the word FRESH rather than clean or dry. Wet or soiled pants are likely to cause stress. If you add: *'Nothing is a problem for us,'* the person will often think if it is not a problem for you then it ceases to be a problem for them too.

You can now suggest ***'a little sit'*** and ***'squeeeeeeeze'***. You **may** make a bit of loving fun by showing a squeeze using your whole face and body. The person is most likely to laugh and copy you. If it is safe to leave the person unattended, you can use this chance to pick out clothes for the day.

When it comes to 'toilet activity' our experience is that using expressive language such as a ***'squeeeeeeeze'*** and calling a spade a spade, such as talking about making a ***'wee'*** instead of urinating, works far better with the person in the middle to late stage of dementia. Some people may find using this language challenging or even demeaning, however, this approach has been proven to work, over and over, and the person responds in a positive way and is not offended. Isn't what works what really matters?

Next, bring out two choices of clothing and use these exact words: *"Today, is it your blue shirt/blouse or your green shirt/blouse?"* Ask the question while you hold the two choices out in front, one in each hand. Then move the hand with the garment in question as you ask about that particular piece of clothing. This offer of choice helps the person to stay in control and have their self-esteem boosted. Once a choice is made, you can then repeat this little ritual with skirts or trousers or whatever the appropriate garments.

Before supporting the person in getting dressed, suggest that you will wash their bottom with a warm face washer to freshen them up. Afterwards, if cream is necessary, give the person the jar to hold and enjoy smelling the lovely lavender scent etc. You could then say, *'You have the softest, freshest bottom in the southern/northern hemisphere.'* This will quite likely bring a laugh.

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Help the person to sit down again on the toilet and assist in putting on disposable pants, trousers or skirt, socks and shoes, and then hand them bra or singlet and shirt etc, one at a time, in the right order. Most often the person will prefer to do as much independently as possible. This gives you a chance to make the bed; once again, only if it is safe to leave the person unattended.

Sometimes people with dementia do not like you to strip the bed or remove their washing, so it is easier to do so during mealtimes or when they are busy getting dressed. Rather than saying the bed is wet or clothes are dirty, as this can cause offence and embarrassment, try using the explanation that, *'Today is 'big wash day.'*

Of course, the above are only guidelines and suggestions to explore in developing rituals best suited to the person for whom you care or to your individual residents.

Expect the unexpected; don't take it personally. Bad tempers and outbursts last only for a short time. The most embarrassing and challenging moments will no doubt give the most laughs when you look back on them 'fondly'. Be creative, and try, try, try again.

Be ready to laugh together at the silliest things. Think ritual, not routine, and then joyful moments and easier, more meaningful experiences will ensue for both you and all those in your care.

- **1.7. Truth or Lies.**

When you care for a person with dementia you are bound to experience situations that present challenges due to the resulting clash of your two different realities.

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How do you respond when:

George tells you that his toy dog is sick?

Great confusion and uncertainty exists over when or whether to tell the *truth* or a *white lie*. I would like to explain and clarify here why neither of these approaches is desirable.

In the everyday care of people with dementia, two distinct response techniques are often used:

Telling the Truth as "it is", or

Inventing a *white lie*.

Telling the truth as "it is"

If you tend to use this approach, it may be grounded in strong ethical beliefs and a conviction to always tell the truth.

When you are suddenly faced with one of the above situations, naturally you will tell the person what **you** experience as the truth about **their reality**. You will most likely have empathy for the person when you respond:

George, you don't need to worry. Your dog is not sick. It is only a toy and therefore cannot feel any pain or discomfort.

If you've ever used responses like these in a similar situation, most likely you found that telling the truth did not elicit a positive result. On the contrary, it may well have broken the person's spirit. Try thinking back to a similar situation and be really honest with yourself. What was the person's reaction? Was it sadness, irritation, anger or aggression? Did the person call you a liar?

The clash of realities

The reason telling the **truth** does not work in these situations is due to the clash between your two realities. What you perceive as the truth does not match the perception of truth by the other person.

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This resulting clash may create tension.

White lies

You may have been taught that it is OK to tell a small *white lie* to the person who can't remember. At first glance, *white lies* can seem like a simple solution to difficult and challenging situations. You may have even had a positive experience in stopping certain behaviour - at least for a while. Sometimes too, the telling of a *white lie* can be seen as the most caring approach to ease the person's pain.

Of course, you will show empathy and warmth in your voice when you respond:

George, what if you give the dog to me and I will take it to the vet for you?

However, if you've ever used a response like this one, most likely you will have experienced that though the *white lie* may stop the behaviour momentarily, the same behaviour almost always returns, sometimes even stronger and more persistently. The *white lie* may leave the person feeling manipulated, confused or angry.

Why white lies don't work

White lies only deal with the face value of a situation, not with the underlying needs and feelings. More often, they can leave the person feeling that we don't care and only want them out of our hair. This approach destroys the trust that you have built between you. A *white lie* cannot create a long-term solution because it does not meet the underlying *universal emotional need*.

Finding resolution

The challenge is to find a way in which the two contradicting realities can co-exist in respectful harmony. And there is a way!

The 5 Universal Emotional Needs

People with dementia are usually very well cared for physically, however, their emotional needs are

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often overlooked. Meeting these needs is **the key to preventing suffering and to providing truly enriching experiences.**

The 5 most common emotional needs for all of us, regardless of age, are:

1. to feel needed and useful
2. to have the opportunity to care
3. to have our self-esteem boosted
4. to love and be loved
5. to express emotions freely

Our emotional needs don't disappear just because we grow old or have dementia. The only thing that changes, especially for people with dementia, is the opportunity to have these needs fulfilled in a meaningful way. And you'll be amazed how often the challenging behaviours you come across are linked to these needs. In fact, many of the behaviours we think of as symptoms of dementia can actually be traced back to *unmet emotional needs*.

What's really going on?

When these emotional needs are not met, the person does not just give up. Instead, the person with dementia has an incredible way of compensating for what is missing. In his or her imagination, the person recreates a time when these needs **were** being fulfilled and then bring these memories to life.

These memories fall into 4 categories:

- ~ significant people or animals
- ~ significant places
- ~ significant situations

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~ significant objects.

When **George** says that his toy dog is sick, it is absolutely real for him. In his younger days, he started an animal refuge, which is now a highly regarded facility. In his imagination, George recreates memories of his dogs.

The key questions here are:

What is the Unfulfilled Emotional Need the recreated memory is compensating for?

What is the person attempting to communicate?

Bringing it all together

George no longer feels he has a role, an identity or meaning in his life. Recreating memories of the Animal Refuge boosts his self-esteem and restores his feelings of being needed, useful, able to care, and of giving and receiving love.

Introduce pets to **George's** everyday life and ask him to help look after them. Ensure he receives only the support needed, so he can experience success. Hang bird feeders and place bird baths that he can fill and clean. These are daily jobs that need love, care and attention.

Now, when George says his toy dog is sick, you can respond genuinely and sincerely, '*George, your care and concern for the dog are absolutely wonderful. I know of no-one else who cares so much. We've been looking for someone who could help us look after our cat (or birds or whatever you have). Could I ask you to help? Would that be okay?*'

By tuning in to the person's *unmet emotional needs* and finding creative ways to help fulfil them, you will both experience something truly wonderful. Once you meet the person's needs, the previous difficult behaviour will disappear. People with dementia always prefer to have their needs fulfilled in this reality rather than resort to their memories. The challenge is to enable them to do so.

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