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Guidelines on Communication with people with Dementia		

<b>Guidelines on Communicating with people with dementia</b>	
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Addendum for Communicating with residents with dementia during any outbreak.

Many people with dementia are older and hence at greater risk of being adversely affected by this virus but not all people with dementia are older and the virus affects people of all ages. Having dementia is not believed to increase the risk of contracting the residents who is on any outbreak but people with dementia may find it more difficult to adopt or comply with various protective measures (e.g. linked to hand washing, coughing, distancing, isolation and lockdown) and to obtain necessary support during this difficult time. It is therefore important to be particularly vigilant during the pandemic in order to protect their wellbeing, safety and rights, and to ensure that they and their relatives have the support they need.

During outbreak, and the challenges that it poses, means that people with dementia may find their normal routines disrupted, lack cognitive stimulation, feel lonely and anxious, fear being abandoned and risk depression.

Some people with dementia, especially in the early stages, may cope relatively well and could perhaps provide valuable feedback to staff, and raise awareness about some of the potential challenges for people with dementia during the outbreak.

Others may experience a deterioration of their condition, sleep disturbances, a change in behaviour, self-neglect and premature institutionalisation. Even people with more advanced dementia, who do not fully understand the current situation, may be affected by the loss of support and sense the stress and emotional upheaval caused by outbreak through the people around them and in the media. They may have difficulty understanding 'cocooning' (at home or in residential care), distancing and the use of protective clothing (making it difficult to recognise service providers), resulting in them feeling trapped, abandoned, confused or scared.

Many health and social care professionals, as well as essential support staff with direct contact with residents with dementia, need to isolate themselves, either as a precautionary measure or because they have the virus.. However, people with dementia may put themselves and others at risk of infection if they do not understand, manage or remember

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to comply with such measures (linked to hand washing, coughing and not touching the face, maintaining a distance from others and, where recommended, wearing a mask). Health and social care professions should strive to provide the best possible care and treatment for people with dementia within the constraints of preventive measures and restrictions, and staff shortages, with due attention to the rights, safety and wellbeing of the latter.

In order to achieve this:

- every effort should be made to facilitate contact with relatives and close friends of the person with dementia via phone and online communication, and in residential care homes to facilitate communication via modern technology between residents and relatives and friends
- When appropriate and subject to the agreement of residents with dementia, informal carers and legal representatives should be contacted so as to enable them to contribute towards treatment and care decisions
- Wishes and preferences expressed in advance care directives or life histories have to be respected
- Particular attention should be paid to maintaining routines, providing information whilst not causing distress and providing emotional support to people with dementia
- under exceptional circumstances, such as emergency or end-of-life situations, limited visits from family members should be allowed only if safe for other residents and staff
- Despite lack of resources, emotional stress and staff shortages, physical, mechanical and chemical restraint should not be used to manage difficult care situations. In extreme cases, if absolutely essential for the safety of the person concerned, any such use should be in accordance with legal requirements (e.g. for authorisation, supervision, documentation, proportionality and revision).

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## **Guidelines on Communication with Residents who have Dementia.**

Communicating with people with dementia requires a special focus. These guidelines give an assistance in helping to improve communication and to assist staff to understand what residents with dementia are attempting to communicate. The following outlines some aids to dealing with communication.

### **1.0. Animal-assisted therapy**

Animal-assisted therapy, at its most basic, means including animals in therapeutic work with humans. There are many ways that animals can be included when working with humans, such as in counselling, teaching/education, rehabilitation, physiotherapy and occupational therapy, disaster relief, as humorous relief, as comfort and to assist in learning life skills, social skills or other key behaviours, to name a few.

When a professional incorporates an animal into their therapeutic practice, they find ways of allowing the animal to extend and facilitate their goals, based on their training and theoretical orientation. A counsellor, for example may incorporate the use of a dog to explore and draw out issues of anger or attachment. Physical therapists may use handling of a small animal or grooming a horse in a motor-skills programme, or dog walking in a fitness or strength-training programme.

### **2.0. Memory Scrapbooks for Reminiscing**

A Memory Scrapbook is a wonderful idea both in its creation as an activity to share with a person who has dementia and to enjoy as a finished product.

You can bring to life special areas of the person's past interests, experiences or skills. You can include many different items of significance including cut-outs, maps, photos, bits of cloth, small tools, programs, invitations, etc.

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For example, a man who may have been involved in wartime service could have a scrapbook that includes badges, pictures of wartime machinery, maps, newspaper cuttings, photos of his mates and so on.

The beauty of this idea is that it can be used equally successfully to elicit memories for the person by a family member, friend, volunteer or staff member.

### 3.0. **Developing Meaningful Relationships**

New research shows developing intimate and meaningful relationships with residents is central to enhancing the resilience of aged care nurses. The notion of making a difference to the lives of older people and sharing these experiences with colleagues also fosters workplace satisfaction.

Research also shows that staff clearly valued long-term, close and intimate relationships with residents and their families. These ties help to buffer staff from some of the pressures of the job. Staff view these relationships as deeply satisfying and a key reason for remaining in aged care, and out of the hospital sector.' A sense of pride and personal satisfaction is also facilitated by a philosophy of person-centred care.

### 4.0 **Finding the message in 'Symbolic Language'**

What does it mean when Ivy takes her dentures out every morning and places them between two slices of bread?

Why does Lorna call out in a loud, accusing voice,  
'My porridge is poisoned!'

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 deep symbolic language. By focusing on the messages conveyed through rich symbolism, we can move towards a deeper understanding of the individual

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person.

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 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 and non-material, for their inspiration.

## 5.0 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. Medically, the resident's statements may be labelled hallucinatory or delusional and lead to her being medicated, resulting in the disrespectful side effects of withdrawal; immobility and incontinence.

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Since it was known that the resident did not have a psychiatric illness, her statement was a clever and symbolic way of telling her carers that not only were her emotional and spiritual needs not being met, but the way she was being treated was destroying her spirit.

## 6.0 Memories.

Events that we experience intensely are stored '3 dimensionally' in our long-term memory. These intense memories have to be out-of-the-ordinary, highly emotional and involve all our senses.

These 3-dimensional memories can be triggered by smell, emotions, songs, thoughts, pictures, tastes and touch. They are stored in many places in the brain at the same time and are not easily damaged by brain changes. People with dementia still have access to these 3-dimensional memories, both the fond and those that are not so happy.

This explains why a person with dementia can vividly recall events from the past in detail, yet they may not be able to remember today's date or the name of the person they are with. The key to unlocking the unique personality of a person with dementia is to enable them to access fond 3-dimensional memories. This is why reminiscence and sensory stimulation work so well.

## 7.0. The experience of the Person with Dementia

A Native American saying says, 'You cannot know a person until you have walked two moons in their moccasins.' Nowhere is this more apt than in understanding the person with dementia. Frustration comes from seeing situations only from our point of view because we are 'blinkered' by our own expectations and experiences. When the person with dementia does not react as we expect, we feel that they have let us down or are trying to make our lives difficult. When we understand where they are coming from, our focus, expectations and perceptions change.

When a person with dementia says something which is 'untrue' in our reality and makes up

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little 'stories' to fill in the memory gap, it is very easy to become irritated and frustrated in a caring role. However, if we 'step into their shoes', we understand that as they begin to feel control slipping away, the person with dementia will fight hard maintain the facade of normality and preserve their self-identity.

## 8.0 Lifting a person's spirits

Spirit is the driving force that lies at the core of our being, the inner light that gives passion, meaning and purpose to our lives.

We need to be as concerned about breaking someone's spirit as we are about someone breaking his or her leg. When we provide care, there is often a strong focus on preventing falls or providing for physical needs. We need to make it equally important to prevent the breaking of the human spirit by focusing on how we can instead ignite and lift the spirit.

The wellbeing of the human spirit is seen as a sparkle in the eyes of a person whose spirit is strong and healthy. Praise and encouragement are a great place. When you praise a person with dementia, you must think of them as an adult and an equal whom you respect. Before you even speak, what you think is what you will show.

## 9.0 Lie or not lie

You may have told small white lies to the person with dementia as they can seem like a simple solution to challenging situations may have even stopped certain behaviour - at least for a while.

White lies may stop the behaviour momentarily, however it almost always returns, sometimes stronger and more persistently. White lies only deal with the face value of a situation and cannot create a long-term solution because they do not meet the underlying universal emotional need.

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The challenge is to find a way in which two contradicting realities can co-exist in respectful harmony. In between your factual reality and the limitless reality of the person with dementia lies the shared realm of universal emotional needs. This is the key to resolution. Here you will always be able to find answers to many challenging questions. This is where everything is right and nothing is wrong because everyone experiences these same emotional needs.

## 10.0 Money Matters

Issues surrounding money are a common occurrence for people who have dementia and their carers, often resulting in frustration for everyone involved.

Repeated trips to the bank or uncharacteristic large purchases and repeatedly checking their bankbook or counting money enables the person with dementia to experience the feeling that they can pay their way and that they have status and worth. Money represents power.

One solution to these challenges is to ensure the person always has cash money at hand. For the person with dementia, it may be of greater importance to have a large quantity of coins and bills rather than the monetary value of each note. Coins that are physically large may also be more valuable to a person with dementia than smaller coins.

## 11.0 Accusations of Stealing

Whilst it may seem unfair and unfounded, the primary carer is often the person on the receiving end of an accusation of stealing.

To understand how this can happen, it is necessary to shift your focus from your own point of view to the experience of the person with dementia. If the person with dementia interprets that the primary carer has contributed to their experience of losing control, they may express their frustration symbolically by accusing them of stealing their money - their self-worth. Avoid arguments, as this will only escalate the situation.

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Address the person's unmet emotional needs by enabling them to feel needed and useful, to have their self-esteem boosted, and identify any roles they can still fulfil, no matter how small. You could experiment with simple solutions such as enabling the person to have input into their daily menus, ask for their opinion on purchases, request help wherever possible, or give the person receipts to check if they are still able.

Issues surrounding money are a common occurrence for people who have dementia and their carers, often resulting in frustration for everyone involved.

These challenges can be experienced in different ways, including:

1. A strong urge to go to the bank to take out money
2. Making purchases over and above their usual habits
3. A strong need to check transactions in their bankbooks
4. Constantly checking their wallet/purse
5. Repetitively counting their money
6. Hiding money about the house
7. Accusing others of stealing
8. Misplacing bills in unusual places
9. Bills/accounts not being paid

These scenarios of uncharacteristic behaviours can be of concern to those caring for a person with dementia.

## 12.0 Im being Poisoned

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

Statements such as, 'I'm being poisoned!' can be a clever and symbolic way of expressing that their emotional and spiritual needs are not being met. Spirit is referred to 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.

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When trying to elicit the symbolic meaning behind a statement such as, 'I'm being poisoned!' work from the assumption that this statement shows the state of the person's spirit and represents a social, emotional or spiritual need that is not being met either now or in the past.

### 13.0 Unexpected Situations

You have asked Betty for a hand with the dishes and suggested she does the drying but instead, she starts washing the dishes. You could choose to correct Betty or tell her off but this would only create suffering and a loss of self-esteem.

Ask yourself this helpful question, '*Does it REALLY matter?*' If the answer is, '*No!*' then make a big fuss out of her initiative approach. Say, '*Betty, you are simply the best. You get right in there and get on with it. What would we do without you!*'

### 14.0 Active Listening

Show with your body language that you are truly there for the other person by bending slightly forward while ensuring you are just below their eye level. This may be different to what you may have learned previously as most teachings say that you should be at the same eye level because this implies you are equal. However, by being just below their eye level you are sending the message that the person with dementia is the important person; they are in control.

This is so empowering for the person with dementia who may have lost control and is no longer feeling important.

### 15.0 Treasure Troves

When a person with dementia 'takes' another person's belongings, they firmly believe the items are their own. Accusing a person with dementia of stealing will only backfire and

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they are likely to become irritated, angry, or even aggressive.

When the social inhibitions that normally regulate responses lift in a person with dementia, rules and beliefs about what is socially acceptable disappear. This means that when a person is attracted to an object, they may instantly pick it up and believe it is theirs!

Ensure you have a relaxed and respectful attitude towards this behaviour and go with the flow of the experience rather than reprimanding or trying to take the object away. Consider setting aside a special area full of attractive or unusual objects that will appeal to the person with dementia. These treasure troves provide a special place where you can direct the person with excitement and ease.

#### **16.0 Weekday or Weekend**

The person with dementia may find it difficult to differentiate between weekdays or the weekends, particularly if routines are the same everyday.

On a Saturday, you could try baking a special cake with colourful, unusual decorations or have a regular morning tea so the sights, smells and tastes are linked to Saturday. The theme could vary from week-to-week and be a symbolic representation of what you have planned for the weekend such as a football or gardening gloves. The sky is the limit!

On a Sunday, help the person dress in their 'Sunday Clothes'. People with dementia only need to have an experience about three times before a link is made and when they smell your special Saturday cake or see their Sunday clothes they may spontaneously say, 'Ah, It must be the weekend!'

#### **17.0 Power of Words**

When you communicate with someone who has lost most of their vocabulary, but uses, 'Yes' or 'No', you can still interact by allowing them to lead you.

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You can ask questions such as: 'Have you.....?' 'Did you.....?' 'Do you.....?'

These questions only require a 'Yes' or 'No' answer and enable the person with dementia to show you where they are in their own reality.

If you ask these questions genuinely and sincerely, there are no side effects. The person with dementia will forgive a great deal, even if you ask the wrong questions. So even if you get no response, simply ask another question. Experiment with the technique and play at being a 'detective' to work out what the person with dementia is trying to communicate.\_\_