

Putdowns and uplifts: signs of good or poor dementia care

The 'new culture' of care has enabled caregivers to identify and avoid negative ways of relating to people with dementia. In the fourth article in our series on DCM, Daniel Kuhn and Jane Verity marry these 'putdowns' with the other side of the coin: positive 'uplifts' that enhance well-being



Daniel Kuhn, director of education, Mather Institute on Aging, Mather Lifeways, Evanston, Illinois, USA;

Jane Verity, director, Dementia Care Australia, Mooroolbark, Victoria, Australia

In writing about a 'malignant social psychology' Tom Kitwood (1990, 1997a, 1997b; Kitwood & Bredin 1992) described a variety of ways in which the well-being of people with dementia could be undermined. His description of 17 'personal detractors' points out how they can be dehumanised by care staff and how awareness of such negative attitudes and behaviour could bring about change for the better. In this consciousness raising effort, Kitwood and Benson (1995) further contrasted the 'old culture' of dementia care characterised by command and control of persons with dementia with a 'new culture' marked by human respect and freedom. In this article, we build upon this work by describing a corresponding list of 17 ways in which personhood can be recognised and reinforced.

Based on extensive observations of people with dementia, we consider personal detractors or what we commonly refer to as 'putdowns' to be helpful in pointing out poor care practices. They indirectly point the way to a person-centred approach by bringing to awareness dehumanising behaviours of what not to do. There is, however, no systematic guide or clear framework for taking note of positive events that can help improve staff attitudes.

In order to enable care staff to embrace holistic care and positive values, an emphasis needs to be placed on identifying instances in which a person with dementia is uplifted by staff. In this way, staff can take pride in their efforts and better understand the impact of their work on the well-being of people in their care. Moreover, new staff can learn by good examples of individualised care and become acquainted with the values of the new culture of dementia care. Therefore, we propose a set of 'uplifts' that enrich the quality of life of people with dementia.

The language of personal detractors is intended to evoke an emotional response for the sake of changing attitudes. It is therefore negative, in some cases even harsh. Each of the 17 categories consists of a passive noun, emphasising their impersonal and chilling effects on persons with dementia. In contrast, we rely upon active verbs to describe ways that staff can make a positive difference in enhancing the life of people in their care. We will describe these contrasting terms and illustrate each one with case examples.

Treachery vs to be supportive

Treachery refers to forms of deception to distract, manipulate, or force someone into compliance. People with dementia will believe us if we tell them what they want to hear. They can often be deceived because of impaired memory and judgment. Treachery involves taking advantage of their cognitive deficits and overpowering them with our superior wits. Telling lies and 'therapeutic fibs' may make things go easier for staff but such deceptive practices undermine personhood. On the other hand, to be supportive of persons with dementia involves accepting their cognitive deficits as a disability yet viewing them as moral equals. This means we need to give full support to their views, their feelings and experiences – no matter how distorted or challenging these may seem. Their perceptions should be accepted.

A common scenario illustrates the difference between treachery and loyalty. A daughter has just left a care facility after a visiting her mother with dementia. Seeing that the resident is crying after the daughter's departure, a staff member attempts to 'reassure' her by saying, 'No need to feel upset. Your daughter is just having a cup of tea – she'll be back in a short time.' Although well meaning, the statement is false and does not address the resident's emotional needs. Alternatively, the staff member might hug the resident and say in a caring tone of voice, 'I know you are upset when your daughter leaves. How about we take a walk together and then I make you a cup of tea?' This statement is intended to meet the resident's need for closeness and kindly redirects her to a pleasurable activity.

Disempowerment vs to empower

Disempowerment involves not allowing people with dementia to use their remaining abilities and failing to help them to complete actions that they have initiated. In contrast, in seeking to empower them, we actively look for ways to help them feel successful and put them back in control of their own lives.

For example, a staff member might handle all the steps of dressing a resident with dementia although the person is able to complete this task given time and encouragement. After all, it may be rationalised that it is necessary to overlook the resident's abilities in order to get the task of

dressing done efficiently. In contrast, the resident's clothes might be laid out in proper sequence and the resident could be talked through each step of dressing and genuinely acknowledged for successfully completing the task. Although time consuming, this person-centred approach fosters well-being.

Infantilisation vs to honour

Infantilisation refers to treating people with dementia in a patronising or condescending manner, as an insensitive parent might treat a very young child. In contrast, to honour someone with dementia means honouring the essence of the human being, regarding each person as a complete individual with a unique personal history, and drawing on that person's strengths and resources instead of narrowly focusing on a current state of disability.

For instance, a staff member might disapprovingly remark after noticing a resident has become incontinent, 'Oh yuk! What a terrible smell you've made! Your incontinence pad needs changing right now.' In contrast, the same situation might be addressed compassionately with honour and regard if the staff member asks the resident, 'Anna, may I help you to your room to freshen up?'

Intimidation vs to empathise

Intimidation refers to inducing fear through threats, coercion, or physical power. In contrast, to empathise with people with dementia means to get at the root of their discomfort or resistance to care by addressing their needs first and foremost. It involves respecting their perspective by listening to underlying needs. The person's viewpoint is always considered, no matter how distorted it may appear.

For example, a staff member gives George his dentures but he refuses them. In response, the staff member might say, 'If you don't put them in your mouth, you will not get dinner today.' George may give in to this threat for fear of missing a meal, but he has been disrespected in the process and is reminded that he has little or no power in this place. On the other hand, a staff member might explore options with him by saying, 'George, is there something wrong with your dentures?' or 'Do you prefer to eat without your dentures today?'

Labelling vs to be descriptive

Labelling refers to using a category or word such as 'demented', 'wanderer', 'sundowner' etc as the basis for interacting with a person and for explaining behaviour. This involves putting the experience of people with dementia into boxes of our own making instead of describing their

To pace is to recognise the slowed abilities of the person with dementia, each in his/her own way, and to adapt one's speech and behaviour accordingly. Someone who keeps pace remembers that it is the responsibility of the sender to ensure the message is received

subjective experience. This tendency alienates us from their human-ness and instead turns them into lesser beings. To be descriptive, however, is to understand the complex nature of human behaviour and to use as many words as possible to describe the many facets of each person objectively. One diagnosis or label is not sufficient to replace the name of a person with dementia, describe unmet needs or sum up an entire lifetime.

For example, referring to a person simply as 'a feeder' is dehumanising for all concerned. Describing this same person in terms of someone who can use utensils if assisted to do so focuses on the ability that is still intact and recognises the fact that this person would still prefer to eat unassisted. Or, instead of staff members announcing, 'Let's get the sundowners distracted before they start acting up' a more descriptive staff member might say, 'I can see that Sally, George, and Ida are getting a bit restless. Let's invite them to the lounge and sing some songs together.' Labels are a convenient and brief means of representing others and their experience. To be descriptive means to use as many words as necessary in order better understand the experience of others from their unique perspective.

Stigmatisation vs to affirm

Stigmatisation involves treating people as if they were diseased objects, aliens or outcasts. Rather than setting people with dementia apart for what they lack, to affirm is to recognise their humanity. In affirming the personhood of another, there is an effort to identify abilities and downplay disabilities. For example, John has advanced dementia and has been talking unintelligibly for the past 10 minutes. A staff member remarks to another, 'Don't bother with that one'. Pointing to her own

head, she adds, 'There's nothing left up there.' Alternatively, a staff member might make eye contact with John and say, for example, 'John, you have an impish look in your eye. Tell me what's on your mind.'

Outpacing vs to pace

Outpacing is perhaps the most common putdown of all. It involves providing information or presenting choices at a rate too fast for a person to understand, or putting pressure on them to do things more rapidly than they can tolerate. In contrast, to pace is to recognise the slowed abilities of the person with dementia, each in their own way, and to adapt our speech and behaviour accordingly. This involves making necessary accommodations to the disabilities of people with dementia, in much the same way we might walk slowly alongside someone using crutches.

In a care setting, examples of outpacing are readily apparent to the trained eye. For instance, a staff member might say in a hurried voice to a resident, 'Ida, this morning the doctor is coming to see you. After lunch you are going to the hairdresser and tonight your son and daughter-in-law are picking you up for a family get together.' Ida becomes overwhelmed by all of this information given at once. She cannot retain it or understand it. Alternatively, the staff member could tell Ida one thing at a time and perhaps even write down this information to ensure that she has fully understood before taking the next step. Someone who keeps pace remembers that it is the responsibility of the sender to ensure the message is received.

Invalidation vs to validate

Invalidation refers to a failure to acknowledge the subjective reality of a person's experience, especially what they are feeling. In contrast, to validate people with dementia is to accept that their words, behaviour, and feelings are meaningful. Their confusion may require a careful eye or listening ear to figure out at times what they are attempting to convey. No matter how distorted their view of reality may appear to us, what they are experiencing is real to them.

For example, residents often declare after being admitted to a care facility, 'I want to go home.' An inexperienced staff member might reply, 'This is your home now' or 'You are at home' instead of addressing the resident's longing to feel loved, safe or comfortable. In another instance of invalidation, a resident says to a staff member, 'I'm hungry' and is told, 'You should not be hungry. You have just been fed.' Alternatively, a staff member might respect the need being expressed and reply, 'Can I bring you a snack of fruit or some biscuits?' →

Banishment vs to include

Banishment involves sending a person away or excluding them physically or psychologically. To include someone means taking steps to reinforce membership in a group or social situation. It also means making allowances for behaviour that might otherwise be excluded and disapproved of and letting others know about this standard of inclusion.

For example, Fred repeatedly spits out his food at mealtimes while sitting with three other residents. In an exasperated state, a staff member removes Fred from the dining room and into his room without any more food. In contrast, Fred might be quietly asked to refrain from spitting or might be invited to join in eating with a staff member at another table.

Objectification vs to show recognition

Objectification is to treat a person like an object; there is no regard for feelings. For example, a staff member might suddenly push someone in a wheelchair without any prior explanation or permission. To show recognition means to treat the person in a respectful, dignified and personal manner. It is an affirmation of the person's humanity. In another instance, Sally is chatting with other residents when a staff member places a blood pressure cuff on her arm without any explanation. Conversation stops as the staff person goes about the task of taking Sally's blood pressure. Alternatively, the staff member could wait until Sally is back in her room, knocks on her door and ask, 'Sally, may I come in to take your blood pressure?'

Ignoring vs to acknowledge

Ignoring refers to situations in which staff members carry on a conversation or activity as if the person with dementia is not present. On the other hand, to acknowledge someone with dementia is to keep in mind that the person deserves to be acknowledged. For example, staff members talking with each other while assisting residents with eating is a common example of this type of putdown. Alternatively, staff members put aside their need to talk with each other until a better time. They put their whole focus and attention on the residents, enabling them to have a positive social experience while eating their meal.

Imposition vs to promote autonomy

Imposition refers to forcing a person to do something, overriding their desire or denying the possibility of personal choice. On the other hand, promoting autonomy involves recognising personal preferences and offering choices, no matter how small. For example, Virginia is helped to put on a grey dress without any consultation.

Alternatively, a staff member might pick out two of Virginia's favorite dresses and while showing her both choices say, 'Today will it be the blue dress or the orange one?' In this scenario, the number of choices has been narrowed to an understandable level and Virginia can express her preference without a problem.

Withholding vs to be compassionate

Withholding involves refusing to give attention that is requested or to meet an evident need. In contrast, to be compassionate is to simply to give from the heart, to wish to enrich the other person's life and give attention to their needs. For example, Harriet is sitting in a wheelchair and crying out, 'Help me! Help me! Help me!' It is obvious that she is in distress. A staff member declares, 'There she goes again with her attention-seeking behaviour.' Although similar to ignoring, withholding is a more active type of putdown in that the person's presence is acknowledged yet a need for help is not addressed. Alternatively, a staff member might instead greet Harriet warmly, give her a hug and in a caring, loving voice say, 'How can I help you, Harriet?'

Accusation vs to understand

Accusation refers to blaming a person for actions or failures of actions that arise from lack of ability. This is often the result of lack of understanding about the reasons underlying the behaviour. On the other hand, to understand means to recognise that there usually is a reasonable explanation for the behaviour. For example, Stanley is found taking some items from another resident's room and a staff member says, 'You are stealing again. Put those things down. They don't belong to you!' Alternatively, a staff member understands there is a reason for this behaviour, explores with Stanley what he has been looking for, and works on meeting this need in another way.

Disruption vs to stand back

Disruption is suddenly intruding upon or interrupting a person's thought or behaviour. In such instances, staff members put their own agenda ahead of the needs of the person with dementia. However, to stand back is to look at what is happening within the person's current frame of reference and to wait for a good time to intervene. For example, several residents including Betty are enjoying a singing group when a staff member walks into the middle and loudly declares, 'I have not yet bathed Betty... Betty come with me.' On the other hand, the staff member could wait until the group activity has ended and then discreetly asks, 'Are you ready for a warm bath now, Betty?'

Mockery vs to pay respect

Mockery is perhaps the most troubling behaviour to witness firsthand and fortunately it is rarely seen among staff. For example, Elizabeth repetitively makes the sound, 'Ooh! Ooh! Ooh!' In response, a staff member mimics Elizabeth, yells out, 'You sound like a damn foghorn!' and laughs loudly. In contrast, to pay respect involves recognising that a person's impairments do not represent the whole self. Each person is worthy of respect regardless of their capacity or incapacity. Thus, instead of making a hurtful remark, the staff member attempts to understand Elizabeth's mood.

Disparagement vs to encourage

Disparagement is telling a person that they are incompetent, useless or worthless by giving them messages that are damaging to their self-esteem. On the other hand, to encourage is to be sensitive to the things the person with dementia offers to help with, and then find ways to do them successfully. Thus, to recognise each effort will lead to more effort whereas disparaging effort will likely ensure that further effort will not take place. The success of an effort is not measured by the outcome but through appreciation for the process. For example, Mary offers to set the table but is told, 'No, you sit down. You are retired now so we take care of you.' In contrast, staff might say, 'Thank you, Mary! I would love your help. Could you start by folding these napkins?'

Summary

Dementia has traditionally been described in terms of irreversible loss of brain cells leading to deterioration, disability, and death. This pessimistic view stands in stark contrast to Kitwood who envisioned that personhood could be maintained and enhanced until the end of life through what he termed 'positive person work' (1997, p89). This refers to a host of rich interactions between staff and persons with dementia. Good care practices need to be identified, appreciated, taught, and replicated if persons with dementia are to be freed from the myths and mistakes of the old culture of care. Such optimistic work is central to transforming the culture of care and promoting lifelong vitality.

References

- Kitwood T. The dialectics of dementia with particular reference to Alzheimer's disease. *Ageing and Society* 1990; 10: 177-196.
- Kitwood T (1997) *Dementia Reconsidered: The Person Comes First*. Open University Press, Buckingham.
- Kitwood T (ed 1997) *Evaluating Dementia Care: The DCM Method*, 7th ed. Bradford Dementia Group.
- Kitwood T & Bredin K (1992) *Person to Person: A Guide to the Care of Those with Failing Mental Powers*. Gale Centre Publications, Loughton.
- Kitwood T & Benson S (eds 1995) *The New Culture of Dementia Care*. Hawker Publications, London.

Contacts

dkuhn@matherlifeways.com
jane@dementiacareaustralia.com