WELL-BEING PROFILE

VERSION No	1	Bendigo KINDCARE (UK) LTD Nursing Home
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Uses of the Well-being Profile
Well-being profiling can be used to:
- Monitor how individuals are evolving over time;
- Provide a framework and a language for staff to think and talk about the social and emotional needs of people with dementia;
- Base assessments of social and emotional needs on careful observation and listening to what people have to say;
- Underpin care plans addressing social and emotional aspects of care.

What is meant by well-being?
We all have fluctuations in mood as we go through life. There are bad times and good times, ups and downs. Well-being is an estimate of how a person experiences life overall, taking into account the ups and downs (Diener and Larson, 1993). It is a judgment of how a person is evolving, given all that is happening to them and how they feel about it.

How can we influence well-being?
We can influence well-being by looking at a person's profile of ups and downs and thinking about their needs and how they can be met. We cannot move mountains, but little things can make a difference.
Care planning can consider how to:
- Support situations that lead to positive behavioural signs recorded as 'strong' on the profile (e.g. social contact, warmth and affection);
- Promote situations that might generate positive behavioural signs recorded as 'weak' on the profile (e.g. humour, helpfulness);
- Respond to negative behavioural signs (e.g. pain, distress, boredom) in a comforting way;
- Avoid situations that generate negative behavioural signs;
- Minimise the effects of factors that put well-being at risk.

Principles of person-centred care (VIPS) (Brooker, 2004)
1. Value people and take their experiences seriously, regardless of age and when they have cognitive impairment.
2. Treat people as individuals, appreciating how their personality, life history, health status and social environment along with cognitive impairment shape their experience
3. Recognise that each person's experience has its own psychological validity, and make efforts to understand their perspective.
4. Recognise that relationships are important to people, and understand that they need for a supportive social environment which fosters well-being.

Planning and preparation
1. Choose observers (it is a good idea to have more than one person, i.e the key worker HCA)
2. Decide on the period of observation (at least a week)
3. Make sure observers are familiar with the guidelines on the positive and negative indicators
4. Discuss the tips for observation and interpretation (below)
5. Set a time to meet, discuss observations and fill in the profile forms at the end of the observation period.
6. You need accurate, up-to-date observations of behaviour and thoughtful, sensitive judgements about what this behaviour means to fill in a Well-being Profile.

Tips for observation

- Keep an open mind;
- Familiarise yourself with the positive and negative indicators;
- Be on the lookout for the positive and negative indicators during the observation period;
- Be on the lookout for the unexpected as well as ordinary, unremarkable behaviour;
- Be aware of your own bias (for example, it is very common to think that rare but frightening incidents are occurring more frequently than they are because they are so memorable);
- Refer to the guidelines on the positive and negative indicators when filling in a profile.

Tips for interpretation

Interpretation should be guided by the understanding and skills central to the person-centred approach. Start by assuming that:

- There is sense in what people say and do regardless of age and cognitive impairment;
- People are likely to be more aware of their surroundings than they seem;
- People (even people with dementia) have feelings about what is happening to them, they try to manage their feelings in various different ways (e.g. denial, blaming others for mistakes);
- Feelings are not always expressed directly and obvious manner;
- Feelings are often expressed in behaviour.
- Use your emotional intelligence and empathic skills to put yourself into the shoes of each person, and to imagine how things look and feel to them.

POSITIVE **BEHAVIOURAL INDICATORS – GUIDELINES**

1. ***CAN COMMUNICATE WANTS, NEEDS AND CHOICES.*** The person can communicate what they want or need, verbally or non-verbally. They can use words or gestures (or both) to get across what they want or do not want. They can challenge someone who is trying to get them to do something they do not want to do. Aggression provoked by the experience of receiving care (e.g. being told what to do or by feeling frustrated and powerless) can be seen as a sign of being able to communicate wants, needs and choices. (However see also ‘anger and aggression’ under ill-being.) Silence or inactivity can communicate reluctance, fear, pain, disapproval, confusion etc. *(for example ‘strong’ is when the person likes to chat to staff and other residents; ‘weak’ is when the person answers when asked but does not initiate)*
2. ***MAKES CONTACT WITH OTHER PEOPLE.*** The person attempts to make contact with other people, for example by talking, making sounds, waving, touching, using gestures, making eye contact, winking, leaning forwards, holding hand out. It is not necessary to be able to talk to make contact with others. The person is able to initiate contact as well as respond to others.
3. ***SHOWS WARMTH OR AFFECTION.*** The person shows signs of warmth or affection towards other people, and is responsive when others are warm or affectionate with them. Warmth or affection can be directed at visitors, caregivers, animals, dolls or people not actually present such as a dead spouse or absent family members. Words of endearment such as ‘like’, ’love’, words of positive regard such as ‘nice’, ‘pretty’, ‘lovely’, ‘good’, ‘great’ and words of gratitude such as ‘thank you’ are signs of warmth. Also look out for sounds (e.g. cooing and chuckling) and gestures (e.g. holding hands, hugging, stroking, patting, smiling, gazing, kissing, blowing kisses and holding). Also be on the lookout for ‘a fond look in the eyes’, looking bright eyed or animated when a person is present; tracking a person’s movements with the eyes; disguised or ‘rough’ affection shown by gestures like slapping someone on the back.
4. ***SHOWS PLEASURE OR ENJOYMENT.*** The person shows signs of pleasure, enjoyment or happiness in the course of ordinary every day life, for example in response to food and drink, social contact and the sights, sounds and smells of the world around them. Examples: enjoying a good meal, giving a contented sigh when tucked into bed, looking bright-eyed and alert when an entertainer is performing, looking relaxed and dreamy during a hand massage, smiling at a visitor.
5. ***ALERTNESS, RESPONSIVENESS.*** The person responds to their surroundings. They react to an unexpected noise or movement, or can be seen to be watching things that are happening. Different people will be alert to different things e.g. watching other people, looking birds or plants outside the window, noticing features of the building, looking at TV, listening to music. Careful observation is needed to distinguish between vacant stating and someone who is watching the movement of leaves

on a tree, or particles of dust in a sunbeam. People with severe dementia may only be responsive to things in their immediate vicinity.

6. ***USES REMAINING ABILITIES.*** Given appropriate stimulus and encouragement, a person responds to their environment making use of retained abilities. Examples: a person who is able to speak uses speech when spoken to, someone who can walk will walk, someone who can sing will join in when others are singing a favourite song.
7. ***CREATIVE EXPRESSION.*** There is scope for creative expression in many activities, but not all activity is creative. When a person is putting something of him / herself into whatever they are doing, rather than doing it in a 'let's get this over and done with' manner, it will count as creative expression. In particular, music, dancing, visual arts provide opportunities for creative expression.
8. ***CO-OPERATIVE OR HELPFUL.*** The person volunteers help, is willing to help when asked or cooperates when others are helping them. What is important here is willingness to help or cooperate, rather than outcomes. Some attempts to help may not actually be helpful, but the attempt or intention to help or be co-operative is what counts.
9. ***RESPONDING APPROPRIATELY TO PEOPLE/SITUATIONS.*** The person shows awareness of other people's needs or feelings. Examples: moving out of the way to let another person past, giving a hand to someone who needs support, showing concern for someone who is distressed.
10. ***EXPRESSES APPROPRIATE EMOTIONS.*** The person shows emotion in line with their personality. Examples: sadness when a visitor leaves; tears when remembering that someone they cared for is dead; elation after an argument; anger when someone treats them badly; frustration when they try to do something and can't; irritation when others are annoying; boredom when there is nothing to do.
11. ***RELAXED POSTURE OR BODY LANGUAGE.*** The person has times when they are both alert and relaxed, with a calm facial expression and without repetitive movements. Times of blank withdrawal, when alertness is lost, do not count.
12. ***SENSE OF HUMOUR.*** The person expresses a sense of humour, with jokes, comments or actions, or responds to the humorous comments or actions of others with smiles or laughter. This can include laughter when something goes wrong – e.g. a caregiver drops a box of dominoes.
13. ***SENSE OF PURPOSE.*** The person shows that they feel able to make things happen, or have something to contribute. They undertake real or pretend work. Examples: making the movements of cleaning; carrying a bag with a purposeful expression; rummaging in a cupboard; removing cups from the table; helping someone out of a chair.
14. ***SIGNS OF SELF RESPECT.*** The person shows signs of trying to preserve dignity, modesty or self - respect. Examples: Adjusting clothing, taking pleasure in grooming, wiping up spilt food, not wanting to participate in a game because they think it is childish. Resisting help with private matters like toileting; refusing to co-operate when treated in a bossy or patronising manner or reacting angrily to other personal detractions can count as self-respect.

NEGATIVE BEHAVIOURAL INDICATORS AND RISK FACTORS

Behavioural indicators

1. ***PAIN, PHYSICAL DISCOMFORT.*** The person reports pain or discomfort, or there are non-verbal signs such as fidgeting, grimacing, wincing, sighing, holding or rubbing. Pain may be linked to other negative signs such as aggression, anxiety and agitation. It is important to remember that physical discomfort, stiffness and pain are all common in older people. Not being in constant pain is not a reason to dismiss pain as unimportant.
2. ***TENSE BODY.*** Tight muscles in face or any other part of the body.
3. ***AGITATION, RESTLESSNESS.*** The person moves a lot, and in a manner which suggests that they are upset, anxious or uncomfortable rather than purposeful.
4. **ANXIETY, FEAR.** The person reveals anxiety or fear in what they say, their facial expressions, other body language and behaviour. There are a range of instinctive responses to fear which include aggression (fight), running away (flight), staying very still (freeze) and seeking safety in numbers (flock). Also, the attachment system may be activated, in which case the person will seek out an attachment figure to protect them and reassure them. In childhood this is typically mother, and the need to find mother (or father) when alarmed often resurfaces in people with dementia.
5. ***ANGER, FRUSTRATION.*** The person expresses a great deal of anger and frustration. Anger erupts without warning and is persistent. Their anger is very easily triggered and is not necessarily a reaction

to what is happening (e.g. resisting personal care) or what the person believes is happening (e.g. believing that someone is attacking them.)

6. ***DEPRESSION, DESPAIR.*** The person shows several signs of depression such as low mood, lack of interest in usual activities, being unresponsive to pleasant events, being irritable, having multiple physical complaints, loss of appetite, difficulty falling asleep, early waking, disturbed sleep, suicidal thoughts, pessimism, poor self-esteem, negative outlook, symptoms worse in the morning.
7. ***SADNESS, GRIEF.*** The person is persistently sad and grieving.
8. ***LISTLESSNESS, WITHDRAWN.*** The person is frequently unresponsive, and seems to be blank and withdrawn. There are no signs that they are day-dreaming, or occupied in their own mind. Even when given long periods of sustained attention (e.g. 15 minutes) they do not respond.
9. ***BOREDOM.*** The person indicates verbally or non-verbally that they are bored.

Risk factors

1. ***AN OUTSIDER (FEELS/IS DIFFERENT TO OTHERS).*** The person has reason to feel different to the group they are in for any reason (e.g. the only man in a group of women, a Londoner in the Highlands, an Anglican in a Catholic facility, the only homosexual). Comments or jokes about a person's difference, though friendly in tone, may be undermining.
2. ***EASILY 'WALKED OVER' BY OTHERS.*** The person finds it hard to hold their own in a social group. Ways of coping may include being quiet and unassertive, avoiding dominant individuals.
3. ***DISLIKED/FEARED BY OTHERS.*** The person is disliked or feared by other users who may keep away or make unfriendly comments. If they are disliked or feared by staff as well, they may be very socially isolated.
4. ***LACK OF ACTIVITY/STIMULATION.*** The person is not helped to find occupation, lacks appropriate stimulation and is therefore leading a very a dull life.
5. ***TRAUMA AND UNHAPPY PAST EXPERIENCES.*** The person has had traumatic or unhappy experiences. These may influence how they are experiencing their present situation, with memories of the past mingling with perceptions of the present. For example, a nursing home can be confused with a concentration camp, prison, boarding school or hospital. Caregivers with a tough manner or similar characteristics to frightening figures from the past can be mistaken for punishing policemen, teachers, soldiers, jailors, bogeymen or parents.

Reliability of the well – being profile

Well-being is similar to other psychological attributes, in that we should not expect to measure it with the same accuracy as temperature or weight. However, there are particular reasons to think carefully about the reliability of our judgments when considering the well-being of people. For example:

- The signs of well-being may be different, depending upon a person's social environment. As observers are part of the social environment, they will be an influence on the attribute they are observing. (As Kitwood (1997) emphasised, the well-being of a person is influenced by how other people treat them as much as it is by their internal psychological characteristics.)
- The well-being indicators were designed for use by people with a good understanding of the person-centred approach. People who do not take this approach often have different assumptions about what people are experiencing.
- Behavioural signs are open to interpretation. Observers with the same views may well disagree.

However, we can take steps to produce good estimates of well-being. This can be done by:

- Being alert to sources of bias
- Checking the guidance notes;
- Involving several people in the process.

If well-being is being monitored over time, it makes sense to involve the same people on each occasion. In assessing well-being the process (observing, reflecting, discussing) can be as important as the product (the profile). Even when the people involved disagree about a person's well-being and needs, the process of observing a person, thinking about their needs and discussing what might be done to meet them will give them a greater awareness of the person and their care needs.