

Tabled document - 'Spark of life', 16 December

Discover the person, not the disease

Every one of us needs to be understood, but for people with dementia the need is desperate and urgent, writes Tom Kitwood.

When we begin the task of caring for a man or woman who has dementia, what do we see? What do we experience? Even more important, what is our way of seeing, our way of experiencing? What, to use a technical term, is our "frame of reference"? Do we see yet another "case" of late-onset Alzheimer's, multi-infarct dementia, or a possible instance of diffuse Lewy body disease? If so, our primary frame of reference is medical.

Do we see a set of deficits, damages and problem-behaviours, awaiting systematic assessment and careful management? If so, our primary frame of reference is manipulative, tending to turn the person into an object. Both of these "frames" have some value, but I believe that neither should be in the forefront. If those with dementia are to have any hope of continuing to feel that they are valued as persons, above all else they need *understanding*. The need is urgent. For not only are they losing such everyday faculties as memory, planning and judgement; they are losing the very basis for knowing the nature of their predicament, and ultimately for holding onto who they are.

Understanding comes first

The truth, of course, is that every one of us - weak, strong, young, old, clever, stupid, beautiful, ugly - has this deep need. It is essential to know that there are a few people (or even just one) with a clear sense of who we are, how we came to be that way, what we are thinking and feeling, what gives us joy,

what causes us pain and fear. When we are going through times of great trouble, when we are burdened with stress or low in spirits, we especially need to be understood. Without that precious gift, which only others can bestow, we are moving towards the edge of madness. For to be mad, in one of the original senses, is to be no longer in real communication with other living beings; to be utterly alone.

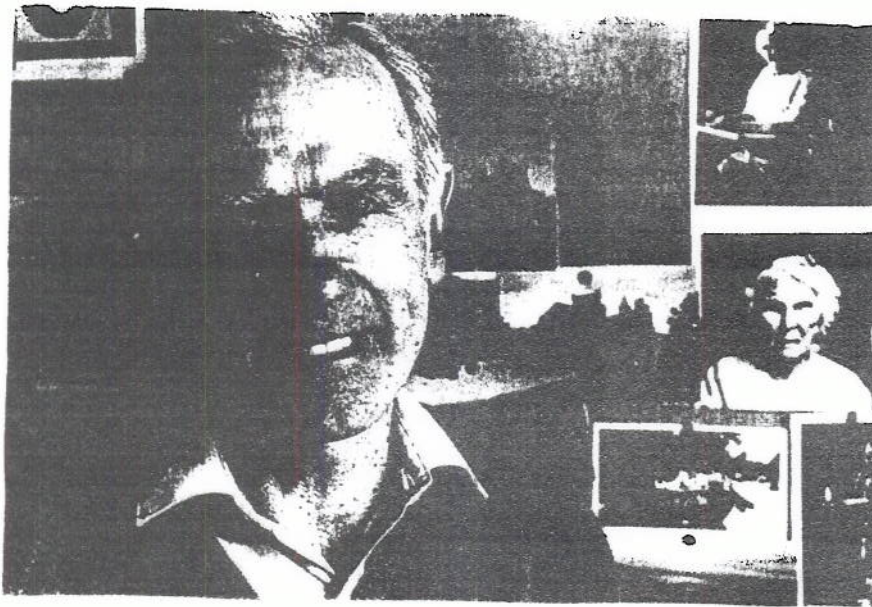
A helpful frame of reference

So - I meet for the first time this woman who, though physically frail, looks stern and forbidding, who gives a ferocious rebuke to anyone who shows kindness to her very friendly dog. I meet for the first time this large, well-dressed and dignified man, who barely seems to acknowledge me but instead stands up and looks as if he's about to make a speech. Both have severe dementia. How am I to understand them, and others in similar situations? What would be a helpful frame of reference?

One basis for understanding is given in the "equation" shown below. (Don't get alarmed! No mathematical knowledge is required).

$$D = P + B + H + NI + SP$$

This is simply to say that any individual's dementia (D) may be considered as the result of a complex interaction between five main components: personality (P), biography (B), physical health (H), neurological impairment (NI) and social psychology (SP). Let us look at each of these in turn.



Tom Kitwood: "If we dare to draw closer, dementia care can become a profound and creative experience".

Personality here means the temperament each individual was born with, together with layer on layer of experience. Sometimes I think of personality as a set of resources (effective, constructive ways of being and doing, learned through success) and, "hang-ups" (blockages, inadequacies, defences, avoidances, learned as a result of fear or hurt). Each one of us has, so to speak, a kit-bag of resources and hang-ups, and as we go on through life we may add to or lose from either set. This kit-bag is brought into the dementing illness; but now there are many new grounds for fear, and some of the former defences against anxiety are stripped away.

Biography refers to what has happened to the person throughout his or her life; relationships, risks, opportunities, adventures, violations, deprivations. In understanding those who have dementia it is particularly important to bear in mind the changes and losses which they may have undergone in recent years. Often the sum total of these is so great that it would overwhelm many people in the prime of life, even if they had no cognitive impairments.

Physical health is important in our understanding for a number of reasons, but two in particular. First, as is well known, there are several conditions which cause confusion, and which can be relieved by straightforward medical means. Second, a person who manifests "problem behaviours" may simply be in discomfort or pain for physical reasons

which he or she cannot express clearly: there is a danger of over-psychologising.

Neurological impairment is, of course, the part of the "equation" that is most talked about; whether we are dealing with neurochemical imbalances and deficits, or some advancing form of pathology in the brain. We should note, however, that the linkages between the dementing illness and what is known about the states of the brain are very far from clear. Also, although many people don't realise it, the ordinary ideas about diseases don't apply. Furthermore, a frame of reference that centres on neurological impairment is, in the short term, impotent; to give a diagnosis of "primary degenerative dementia", however precise and detailed, is to say nothing about how to deliver good care. So neurological impairment can only be a small part of the whole picture.

Finally, there is the social psychology: that is to say, what is happening to the person moment by moment in everyday life as he or she attempts to be, do, relate, communicate – and whether or not there is a helpful and enabling response from others. This, undoubtedly, is the domain in which personhood lies. It is remarkable how little attention has been given to it, especially when compared to the study of the brain. Yet (when health problems have been sorted out as far as possible) it is only in the social psychology that profound and continuing change for the better can be brought about.

We are all in the same boat

Although the neuroscientists didn't intend it, one consequence of focussing primarily on neurological impairment is that it creates an "us" and a "them", and implies a great divide between. "We" have sound brains; "they" have brains that are damaged. "We" are rational; "they" are not. "We" have actions; "they" simply have behaviours. If we look at things this way, there can be no real understanding, for "they" are an alien species. There can, of course, still be assessment, of a kind.

Good care practice, I believe, is founded on the painful truth that both "we" and "they" belong to one humanity. All of us are damaged or deficient in some way; almost all of us carry some Alzheimer-type pathology in the brain. All of us have feelings, intentions, actions with meaning.

To those who wish to keep a distance, it somehow seems natural to adopt either a medical or a manipulative frame or reference. If, however, we dare to draw closer, dementia care can become a profound and creative experience.

As we discover the person who has dementia, we also discover something of ourselves. For what we ultimately have to offer is not technical expertise, but ordinary faculties raised to a higher level: our power to feel, to give, to stand in the shoes (or sit in the chair) of another, through the use of our imagination. At times we may even offer love.

A gentler, kinder pattern for modern life

At present, much is loaded against such rich possibilities. The "epidemic of dementia" is occurring while society is in a deep economic crisis, and when the social structures that might sustain good caring are not in place.

To be committed to understanding, to adopt a frame of reference that puts the person first, is no trivial matter. It is to be at odds with a culture, an inherited social tradition that works in many respects against the person. Good dementia care, then, is one fragment of what may become a gentler, kinder and more understanding pattern for modern life. DC

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