



## **Diverse perspectives on health and illness**

*Valuing people's lives*

### **Presenter**

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You will hear from the late Tom Kitwood, who was the Alois Alzheimer Professor of Psychogerontology, and Head of the Bradford dementia group. Tom's work on dementia care has been seen as the most important innovative, and creative development in a neglected area of study, and here he talks about the key concepts of personhood and well being, that underpin his principles.

### **Tom Kitwood**

This can be summed up in about four things. One, the technical term is agency, but that means being able to make things happen in the world. This is an ability which is established in infants quite early, even something like the ability to make a care giver come through crying. Or I used to play a game with one of my children, which I called 'let's throw teddy out the pram', and this was, the child threw teddy out of the pram and dad brought teddy back again, where upon teddy was thrown out of the pram again, but this was giving the six month old child a sense of 'I can make things happen in the world'. Now, I think that the well being of somebody with dementia, is very much connected with still having the sense that they can make something happen. That's agency.

I would say there's something about a sense of self worth. Very often, accompanying a dementing illness, is a great sense of loss of value, 'I'm no use to anyone any more, I can't do things for anyone any more', and it's crucial, that that sense of value should be maintained as far as possible, and again by the kind of ways in which we directly react with those who have dementia, we can enhance that sense of value. A third thing, is, I would call it social confidence, and meaning by that, not the ability to make fine talk at a dinner party, or something like that, but, more that when I make some movement into the world of persons, of other persons, something is going to come back. So, in other words it's still worth making that move. Now in an extreme form, say in a long stay hospital ward, we might see a person with severe dementia, reaching out a hand as a care worker passes by, that's offering something to the social world.

Now it's crucial for the well being of that person whether or not a hand responds to that or not. And I personally see a lot of the vegetation that's said to accompany dementia, as being, a kind of loss of confidence that these movements into the social world, will receive a response. and then, the fourth thing, and this is perhaps the most subtle and difficult, would be summed up in the word hope. And I'm meaning by that, not a hope for getting better or, a hope that suddenly the pathology in the brain will disappear, but more, that ultimately all will be well, ultimately something will remain stable and secure, under-girding the rest of life.

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Tom and his colleagues developed a a specific method of monitoring behaviour called Dementia Care Mapping. It involves classifying both the behaviour of a person with dementia, and whatever care is given, enabling care workers to reassess, and change their practice.

### **Tom Kitwood**

The standard jargon in dementia care is about problem behaviours. Now, we actually don't use that notion at all, because that is focusing on the care worker. 'Her behaviours or his behaviours, are problems to us'. We have really attempted to re-frame the whole thing, as these, when we do come across these problem behaviours, they're indications of ill being, and need to be fitted into a much broader understanding of what it is to be in a state of ill

being. Now, as soon as we get into this way of thinking, saying, 'What is the person needing, what is the person trying to say to us?' we quickly understand a lot about ill being. The whole situation of care giving in dementia is so fragile, it's not just those who have dementia, who've got problems of self esteem, it's also the care staff who don't know what they're doing. We none of us know clearly what we're doing, we're moving into new territory, very exciting, but unexplored new territory, and so it's not surprising that those who give care, have weak self esteem, and at times themselves resort to ways that they know, because that's giving them some security. So there's a tremendous amount of growing to don all sides. Possibilities for the dementia person to grow, and possibilities for those who are giving care to grow.

**Presenter**

So how would Tom describe Dementia Care Mapping?

**Tom Kitwood**

The overall purpose is, to find out what is going on, in order to bring about improvements. So ultimately I would see Dementia Care Mapping as a kind of ethical tool, or a moral instrument one might say, which has got at heart the desire to sustain and maintain the personhood of those who have dementia. Shed the idea, that the behaviour of persons with dementia is meaningless, rather, seek to understand the behaviour in the context of the situation that now is, and in the context of the life history.