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On being a person

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A few months before this book was completed, a day centre was approached by an agency concerned to promote awareness about Alzheimer's disease and similar conditions. Could the day centre provide some photographs of clients, to be used for publicity purposes? Permission was sought and granted; the photographs were duly taken and sent. The agency, however, rejected them, on the ground that the clients did not show the disturbed and agonized characteristics that people with dementia 'ought' to show, and which would be expected to arouse public concern. The failure of the photographic exercise, from the standpoint of the agency, was a measure of the success of the day centre from the standpoint of the clients. Here was a place where men and women with dementia were continuing to live in the world of persons, and not being downgraded into the carriers of an organic brain disease.

Alzheimer victims, demented, elderly mentally infirm – these and similar descriptions devalue the person, and make a unique and sensitive human being into an instance of some category devised for convenience or control. Imagine an old-fashioned weighing scale. Put aspects of personal being into one pan, and aspects of pathology and impairment into the other. In almost all of the conventional thinking that we have inherited, the balance comes down heavily on the latter side. There is no logical ground for this, nor is it an inference drawn from a comprehensive range of empirical data. It is simply a reflection of the values that have prevailed, and of the priorities that were traditionally set in assessment, care practice and research. The time has come to bring the balance down decisively on the other side, and to recognize men and women who have dementia in their full humanity. Our frame of reference should no longer be person-with-DEMENTIA, but PERSON-with-dementia.

This chapter, then, is concerned with personhood: the category itself, the centrality of relationship, the uniqueness of persons, the fact of our embodiment. Rather than emphasize the differences that dementia brings, we will first celebrate our common ground.

The concept of personhood

The term personhood, together with its synonyms and parallels, can be found in three main types of discourse: those of transcendence, those of ethics and those of social psychology. The functions of the term are different in these three contexts, but there is a core of meaning that provides a basic conceptual unity.

Discourses of transcendence make their appeal to a very powerful sense, held in almost every cultural setting, that being-in-itself is sacred, and that life is to be revered. Theistic religions capture something of this in their doctrines of divine creation; in eastern traditions of Christianity, for example, there is the idea that each human being is an 'ikon of God'. Some forms of Buddhism, and other non-theistic spiritual paths, believe in an essential, inner nature: always present, always perfect, and waiting to be discovered through enlightenment. Secular humanism makes no metaphysical assumptions about the essence of our nature, but still often asserts, on the basis of direct experience, that 'the ultimate is personal'.

In the main ethical discourses of western philosophy one primary theme has been the idea that each person has absolute value. We thus have an obligation to treat each other with deep respect; as ends, and never as means towards some other end. The principle of respect for persons, it was argued by Kant and those who followed in his footsteps, requires no theological justification; it is the only assumption on which our life as social beings makes sense. There are parallels to this kind of thinking in the doctrine of human rights, and this has been used rhetorically in many different contexts, including that of dementia (King's Fund 1986). One problem here, however, is that in declarations of rights the person is framed primarily as a separate individual; there is a failure to see human life as interdependent and interconnected.

In social psychology the term personhood has had a rather flexible and varied use. Its primary associations are with self-esteem and its basis; with the place of an individual in a social group; with the performance of given roles; and with the integrity, continuity and stability of the sense of self. Themes such as these have been explored, for example, by Tobin (1991) in his work on later life, and by Barham and Hayward (1991) in their study of ex-mental patients living in the community. Social psychology, as an empirical discipline, seeks to ground its discourses in evidence, even while recognizing that some of this may consist of pointers and allusions. Robust measures such as those valued by the traditional natural sciences usually cannot be obtained, even if an illusion is created that they can.

Thus we arrive at a definition of personhood, as I shall use the term in this book. It is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust. Both the according of personhood, and the failure to do so, have consequences that are empirically testable.

The issue of inclusion

As soon as personhood is made into a central category, some crucial questions arise. Who is to be viewed and treated as a person? What are the grounds for inclusion and exclusion, since 'person' is clearly not a mere synonym for 'human being'? Is the concept of personhood absolute, or can it be attenuated?

Such questions have been examined many times, particularly in western moral philosophy. In one of the best-known discussions Quinton (1973) suggests five criteria. The first is consciousness, whose normal accompaniment is consciousness of self. The second is rationality, which in its most developed form includes the capacity for abstract reasoning. The third is agency: being able to form intentions, to consider alternatives, and to direct action accordingly. The fourth is morality, which in its strongest form means living according to principle, and being accountable for one's actions. The fifth is the capacity to form and hold relationships; essential here is the ability to understand and identify with the interests, desires and needs of others. Quinton suggests that each criterion can be taken in

a stronger or a weaker sense. We can make the distinction, for example, between someone who has all the capabilities of a moral agent, and someone who does not, but who is nevertheless the proper subject for moral concern.

With the arrival of computers and the creation of systems with artificial intelligence, doubts began to be raised about whether the concept of personhood is still valid (Dennett 1975). The central argument is as follows. In computers we have machines which mimic certain aspects of human mental function. We can (and often do) describe and explain the 'behaviour' of computers as if they were intentional beings, with thoughts, wishes, plans and so on. However, there is no necessity to do this; it is simply an anthropomorphism – a convenient short cut. In fact the behaviour of computers can be completely described and explained in physical terms. It is then argued that the same is possible, in principle, with human beings, although the details are more complex. Thus an intentional frame is not strictly necessary; and the category of personhood, to which it is so strongly tied, becomes redundant.

Behind such debates a vague shadow can be discerned. It is that of the liberal academic of former times: kind, considerate, honest, fair, and above all else an intellectual. Emotion and feeling have only a minor part in the scheme of things; autonomy is given supremacy over relationship and commitment; passion has no place at all. Moreover the problems seem to centre on how to describe and explain, which already presupposes an existential stance of detachment. So long as we stay on this ground the category of personhood is indeed in danger of being undermined, and with it the moral recognition of people with mental impairments. At a popularistic level, matters are more simple. Under the influence of the extreme individualism that has dominated western societies in recent years, criteria such as those set out by Quinon have been reduced to two: autonomy and rationality. Now the shadowy figure in the background is the devotee of 'business culture'. Once this move is made, there is a perfect justification for excluding people with serious disabilities from the 'personhood club'.

Both the mainstream philosophical debate and its popularistic reductions have been radically questioned by Stephen Post, in his book *The Moral Challenge of Alzheimer's Disease* (1995). Here he argues that it has been a grave error to place such great emphasis on autonomy and rational capability; this is part of the imbalance of our cultural tradition. Personhood, he suggests, should be linked far more strongly to feeling, emotion and the ability to live in relationships, and here people with dementia are often highly competent – sometimes more so than their carers.

Post also suggests a principle of *moral solidarity*: a recognition of the essential unity of all human beings, despite whatever differences there may be in their mental capabilities as conventionally determined. Thus we are all, so to speak, in the same boat; and there can be no empirically determined point at which it is justifiable to throw some people into the sea. The radical broadening of moral awareness that Post commends has many applications in the context of dementia: for example to how diagnostic information is handled, to the negotiation of issues such as driving or self-care, and ultimately to the most difficult questions of all, concerning the preservation of life.

Personhood and relationship

There is another approach to the question of what it means to be a person, which gives priority to experience, and relegates analytic discussion to a very minor place. One of its

principal exponents was Martin Buber, whose small book *Ich und Du* was first published in 1922, and later appeared in an English translation, with the title *I and Thou*, in 1937. It is significant that this work was written during that very period when the forces of modernization had caused enormous turmoil throughout the world, and in the aftermath of the horrific brutalities of the First World War.

Buber's work centres on a contrast between two ways of being in the world; two ways of living in relationship. The first he terms I-It, and the second I-Thou. In his treatment of Thou he has abstracted one of many meanings; making it so to speak, into a jewel. In older usage it is clear that a person could be addressed as Thou in many forms of 'strong recognition': command, accusation, insult and threat, as well as the special form of intimacy that Buber portrays. Relating in the I-It mode implies coolness, detachment, instrumentality. It is a way of maintaining a safe distance, of avoiding risks; there is no danger of vulnerabilities being exposed. The I-Thou mode, on the other hand, implies going out towards the other; self-disclosure, spontaneity – a journey into uncharted territory. Relationships of the I-It kind can never rise beyond the banal and trivial. Daring to relate to another as Thou may involve anxiety or even suffering, but Buber sees it also as the path to fulfilment and joy. 'The primary word I-Thou can only be spoken with the whole being. The primary word I-It can never be spoken with the whole being' (1937: 2).

Buber's starting point, then, is different from that of western individualism. He does not assume the existence of ready-made monads, and then inquire into their attributes. His central assertion is that relationship is primary; to be a person is to be addressed as Thou. There is no implication here that there are two different kinds of objects in the world: Thous and Its. The difference lies in the manner of relating. Thus it is possible (and, sad to say, all too common) for one human being to engage with another in the I-It mode. Also it is possible, at least to some degree, to engage with a non-human being as Thou. We might think, for example, of a woman in her 80s whose dog is her constant and beloved companion, or of a Japanese man who faithfully attends his bonsai tree each day.

In the English language we have now almost lost the word Thou. Once it was part of everyday speech, corresponding to the life of face-to-face communities. Its traces remain in just a few places still, for example in North country dialects, and in old folk songs such as one about welcoming a guest, which has the heart-warming refrain:

Draw chair raight up to t'table;
 Stay as long as Thou art able;
 I'm always glad to see a man like Thee.

Among minority groups in Britain, the Quakers were the last to give up the use of Thou in daily conversation, and they did so with regret. Their sense of the sacredness of every person was embedded in their traditional form of speech.

One of the most famous of all Buber's sayings is 'All real living is meeting' (1937: 11). Clearly it is not a matter of committees or business meetings, or even a meeting to plan the management of care. It is not the meeting of one intellectual with another, exchanging their ideas but revealing almost nothing of their feelings. It is not the meeting between a rescuer and a victim, the one intent on helping or 'saving' the other. It is not necessarily the meeting that occurs during a sexual embrace. In the meeting of which Buber speaks there is no ulterior purpose, no hidden agenda. The ideas to be associated with this are openness, tenderness, presence (present-ness), awareness. More than any of these, the word that captures

the essence of such meeting is *grace*. Grace implies something not sought or bought, not earned or deserved. It is simply that life has mysteriously revealed itself in the manner of a gift.

For Buber, to become a person also implies the possibility of freedom. ‘So long as the heaven of Thou is spread out over me, the wind of causality cowers at my heels, and the whirlwind of fate stays its course’ (1937: 9). Here, in poetic language, is a challenge to all determinism, all mechanical theories of action. In that meeting where there is full acceptance, with no attempt to manipulate or utilize, there is a sense of expansiveness and new possibility, as if all chains have been removed. Some might claim that this is simply an illusion, and that no human being can escape from the power of heredity and conditioning. Buber, however, challenges the assumption that there is no freedom by making a direct appeal to the experience of the deepest form of relating. It is here that we gain intuitions of our ability to determine who we are, and to choose the path that we will take. This experience is to be taken far more seriously than any theory that extinguishes the idea of freedom.

Buber’s work provides a link between the three types of discourse in which the concept of personhood is found: transcendental, ethical and social-psychological. His account is transcendental, in that he portrays human relationship as the only valid route to what some would describe as an encounter with the divine. His account is ethical, in that it emphasizes so strongly the value of persons. It is not, however, a contribution to analytic debate. For Buber cuts through all argumentation conducted from a detached and intellectualized standpoint, and gives absolute priority to engagement and commitment. Against those who might undermine the concept of personhood through analogies from artificial intelligence, Buber might simply assert that no one has yet engaged with a computer as Thou.

In relation to social psychology, we have here the foundation for an empirical inquiry in which the human being is taken as a person rather than as an object. There is, of course, no way of proving – either through observation or experiment – whether Buber’s fundamental assertions are true or false. Any attempt to do so would make them trivial, and statements that appeal through their poetic power would lose their meaning. (It would be equally foolish, for example, to set about verifying the statement ‘My love is like a red, red rose, that’s newly sprung in June’.) The key point is this. Before any kind of inquiry can get under way in a discipline that draws on evidence, assumptions have to be made. Popper (1959) likened these to stakes, driven into a swamp, so that a stable building can be constructed. These assumptions are metaphysical, beyond the possibility of testing. Thus, in creating a social psychology, we can choose (or not) to accept these particular assumptions, according to whether they help to make sense of everyday experience and whether they correspond to our moral convictions (Kitwood and Bredin 1992a).

To see personhood in relational terms is, I suggest, essential if we are to understand dementia. Even when cognitive impairment is very severe, an I–Thou form of meeting and relating is often possible. There is, however, a very sombre point to consider about contemporary practice. It is that a man or woman could be given the most accurate diagnosis, subjected to the most thorough assessment, provided with a highly detailed care plan and given a place in the most pleasant surroundings – without any meeting of the I–Thou kind ever having taken place.

The psychodynamics of exclusion

Many cultures have shown a tendency to depersonalize those who have some form of serious disability, whether of a physical or a psychological kind. A consensus is created, established

in tradition and embedded in social practices, that those affected are not real persons. The rationalizations follow on. If people show bizarre behaviour 'they are possessed by devils'; 'they are being punished for the sins of a former life'; 'the head is rotten'; 'there is a mental disorder whose symptoms are exactly described in the new diagnostic manual'.

Several factors come together to cause this dehumanization. In part, no doubt, it corresponds to characteristics of the culture as a whole; where personhood is widely disregarded, those who are powerless are liable to be particularly devalued. Many societies, including our own, are permeated by an ageism which categorizes older people as incompetent, ugly and burdensome, and which discriminates against them at both a personal and a structural level (Bytheway 1995). Those who have dementia are often subjected to ageism in its most extreme form; and, paradoxically, even people who are affected at a relatively young age are often treated as if they were 'senile'. In financial terms, far too few resources have been allocated to the provision of the necessary services. There is also the fact that very little attention has been given to developing the attitudes and skills that are necessary for good psychological care. In the case of dementia, until very recently this was not even recognized as an issue, with the consequence that many people working in this field have had no proper preparation for their work.

Behind these more obvious reasons, there may be another dynamic which excludes those who have dementia from the world of persons. There seems to be something special about the dementing conditions – almost as if they attract to themselves a particular kind of inhumanity: a social psychology that is malignant in its effects, even when it proceeds from people who are kind and well-intentioned (Kitwood 1990d). This might be seen as a defensive reaction, a response to anxieties held in part at an unconscious level.

The anxieties seem to be of two main kinds. First, and naturally enough, every human being is afraid of becoming frail and highly dependent; these fears are liable to be particularly strong in any society where the sense of community is weak or non-existent. Added to that, there is the fear of a long drawn-out process of dying, and of death itself. Contact with those who are elderly, weak and vulnerable is liable to activate these fears, and threaten our basic sense of security (Stevenson 1989). Second, we carry fears about mental instability. The thought of being insane, deranged, lost forever in confusion, is terrifying. Many people have come close to this at some point, perhaps in times of great stress, or grief, or personal catastrophe, or while suffering from a disease that has affected mental functioning. At the most dreadful end of these experiences lies the realm of 'unbeing', where even the sense of self is undermined.

Dementia in another person has the power to activate fears of both kinds: those concerned with dependence and frailty, and those concerned with going insane. Moreover, there is no real consolation in saying 'It won't happen to me', which can be done with many other anxiety-provoking conditions. Dementia is present in almost every street, and discussed repeatedly in the media. We know also that people from all kinds of background are affected, and that among those over 80 the proportion may be as high as one in five. So in being close to a person with dementia we may be seeing some terrifying anticipation of how we might become.

It is not surprising, then, if sensitivity has caused many people to shrink from such a prospect. Some way has to be found for making the anxieties bearable. The highly defensive tactic is to turn those who have dementia into a different species, not persons in the full sense. The principal problem, then, is not that of changing people with dementia, or of 'managing' their behaviour; it is that of moving beyond our own anxieties and defences, so that true meeting can occur, and life-giving relationships can grow.

The uniqueness of persons

At a commonsensical level it is obvious that each person is profoundly different from all others. It is easy to list some of the dimensions of that difference: culture, gender, temperament, social class, lifestyle, outlook, beliefs, values, commitments, tastes, interests – and so on. Added to this is the matter of personal history. Each person has come to be who they are by a route that is uniquely their own; every stage of the journey has left its mark.

In most of the contexts of everyday life, perhaps this kind of perception will suffice. There are times, however, when it is essential to penetrate the veil of common sense and use theory to develop a deeper understanding. It is not that theory is important in itself, but that it can challenge popular misconceptions; and it helps to generate sensitivity to areas of need, giving caring actions a clearer direction (Kitwood 1997a).

Within conventional psychology the main attempt to make sense of the differences between persons has been through the concept of personality, which may roughly be defined as ‘a set of widely generalised dispositions to act in certain kinds of way’ (Alston 1976). The concept of personality, in itself, is rich enough to provide many therapeutic insights. However, by far the greatest amount of effort in psychology has been spent in attempts to ‘measure’ it in terms of a few dimensions (extraversion, neuroticism, and so on), using standard questionnaires – personality inventories, as they are often called. The questions tend to be simplistic and are usually answered through self-report. This approach does have some value, perhaps, in helping to create a general picture, and it has been used in this way in the context of dementia. The main use of personality measurement, however, has been in classifying and selecting people for purposes that were not their own. Psychometric methodology is, essentially, a servant of the I–It mode.

There is another approach within psychology, whose central assumption is that each person is a meaning-maker and an originating source of action (Harré and Secord 1972; Harré 1993). Because of its special interest in everyday life it is sometimes described as being ethogenic, by analogy with the ethological study of animals in their natural habitats. Social life can be considered to consist of a series of episodes, each with certain overriding characteristics (buying a pot plant, sharing a meal, and so on). In each episode the participants make their ‘definitions of the situation’, usually at a level just below conscious awareness, and then bring more or less ready-made action schemata into play. Interaction occurs as each interprets the meaning of the others’ actions. Personality here is viewed as an individual’s stock of learned resources for action. It is recognized that one person may have a richer set of resources than another, and in that sense have a more highly developed personality. A full ‘personality inventory’ would consist of the complete list of such resources, together with the types of situation in which each item is typically deployed.

This view can be taken further by assimilating to it some ideas that are central to depth psychology and psychotherapeutic work. The resources are of two main kinds, which we might term *adaptive* and *experiential*. The first of these consists of learned ways of responding ‘appropriately’ to other people’s demands (both hidden and explicit), to social situations, and to the requirements of given roles. The process of learning is relatively straightforward, and is sometimes portrayed as involving imitation, identification and internalization (Danziger 1978). The second kind of resource relates to a person’s capacity to experience what he or she is actually undergoing. Development here occurs primarily when there is an abundance of comfort, pleasure, security and freedom. In Jungian theory

the adaptive resources correspond roughly to the ego, and the experiential resources to the Self (Jung 1934). The term that I shall use for the latter is 'experiential self'.

In an ideal world, both kinds of personal resource would grow together. The consequence would be an adult who was highly competent in many areas of life, and who had a well-developed subjectivity. He or she would be 'congruent', in the sense used by Rogers (1961): that is, there would be a close correspondence between what the person was undergoing, experiencing, and communicating to others. In fact, however, this is very rarely the case. The development of adaptive resources is often blocked by lack of opportunity, by the requirements of survival, and sometimes by the naked imposition of power. The growth of an experiential self is impeded where there is cruelty or a lack of love, or where the demands of others are overwhelming. Many people have been subjected to some form of childhood abuse: physical, sexual, emotional, commercial, spiritual. Areas of pain and inner conflict are hidden away, and the accompanying anxiety is sealed off by psychological defences. According to the theorists of Transactional Analysis, this is the context in which each person acquires a 'script' – a way of 'getting by' that makes it possible to function in difficult circumstances (Stewart and Joines 1987). As a result of extreme overadaptation, so Winnicott suggested, a person acquires a 'false self', a 'front' that is radically out of touch with experience and masks an inner chaos (Davis and Wallbridge 1981).

These ideas, which I have sketched here in only the barest outline, can be developed into a many-sided view or model of personal being. As we shall see, it can shed much light on the predicament of men and women who have dementia. Where resources have been lost, we might ask some very searching questions about what has happened and why. If personhood appears to have been undermined, is any of that a consequence of the ineptitude of others, who have all their cognitive powers intact? If uniqueness has faded into a grey oblivion, how far is it because those around have not developed the empathy that is necessary, or their ability to relate in a truly personal way? Thus we are invited to look carefully at ourselves, and ponder on how we have developed as persons; where we are indeed strong and capable, but also where we are damaged and deficient. In particular, we might reflect on whether our own experiential resources are sufficiently well developed for us to be able to help other people in their need.

Personhood and embodiment

Thus far in this chapter we have looked at issues related to personhood almost totally from the standpoint of the human sciences. The study of dementia, however, has been dominated by work in such disciplines as anatomy, physiology, biochemistry, pathology and genetics. If our account of personhood is to be complete, then, we must find a way of bringing the discourses of the human and natural sciences together.

There is a long-standing debate within philosophy concerning the problem of how the mind is related to the body, and to matter itself. The debate first took on a clear form with the work of Descartes in the seventeenth century, and since that time several distinct positions have emerged. I am going to set out one of these, drawing to some extent on the work of the philosopher Donald Davidson (1970), and the brain scientists Steven Rose (1984) and Antonio Damasio (1995). The starting point is to reject the assumption with which Descartes began: that there are two fundamentally different substances, matter and mind. Instead, we postulate a single (exceedingly complex) reality; it can be termed 'material', so long as it is clear that 'matter' does not consist of the little solid particles that atoms were once taken to be.

We can never grasp this reality, as it really is, because of the limitations of our nervous system, but we can talk about it in several different ways. Often we use an intentional kind of language, with phrases such as ‘I feel happy’, ‘I believe that you are telling the truth’, ‘I ought to go and visit my aunt’. Through this kind of language we can describe our feelings, draw up plans, ask people to give reasons for their actions, and so on. Often when we speak and think along these lines we have a sense of freedom, as if we are genuinely making choices, taking decisions, and making things happen in the world.

The natural sciences operate on very different lines. Here the aim is to be rigorously objective, using systematic observation and experiment. Within any one science regularities are discovered, and processes are seen in terms of causal relationships. People who work as scientists sometimes have a sense of absolute determinism. The determinism is actually built in from the start; it is part of the ‘grammar’. We know no other way of doing the thing called natural science.

Each type of discourse has its particular uses. One of the greatest and commonest mistakes is to take the descriptions and explanations given in language as if these were the reality itself. Once that is done, many false problems arise; for example, whether or not we really have free will, whether the mind is inside the brain, whether the emotions are merely biochemical, and so on. There are strong reasons for believing that the reality itself, whatever it may be, is far too complex to be caught fully in any of our human nets of language.

Moving on now to the topic of mind and brain, the basic assumption is that any psychological event (such as deciding to go for a walk) or state (such as feeling hungry) is also a brain event or state. It is not that the psychological experience (ψ) is causing the brain activity (**b**) or vice versa; it is simply that some aspect of the true reality is being described in two different ways.

Hence in any individual, $\psi \equiv \mathbf{b}$

The ‘equation’ simply serves to emphasize the assumption that psychology and neurology are, in truth, inseparable.

It is not known how far experiences which two different individuals describe in the same way have parallel counterparts in brain function; scanning methods which look at brain metabolism do, however, suggest broad similarities (Fischbach 1992).

Now the brain events or states occur within an ‘apparatus’ that has a structure, an architecture. The key functioning part is a system of around ten thousand million (10^{10}) neurones, with their myriads of branches and connections, or synapses. A synapse is the point at which a ‘message’ can pass from one neurone to another, thus creating the possibility of very complex ‘circuits’. So far as is known, the basic elements of this system, some general features of its development, and most of the ‘deeper’ forms of circuitry (older in evolutionary terms), are genetically ‘given’. On the other hand the elaboration of the whole structure, and particularly the cerebral cortex, is unique to each individual and not pre-given. The elaboration, then, is epigenetic: subject to processes of learning that occur after the genes have had their say. Each human face is unique; so also is each human brain.

It is probable that there are at least two basic types of learning: explicit and implicit (Kandel and Hawkins 1992). The former involves, for example, remembering faces and places, facts and theories. The latter involves acquiring skills that have a strong physical component; for example learning to walk, to swim or to play the piano. In both cases, learning is thought to proceed by stages. First, over a period of minutes or hours, existing neurone circuits are modified, by the strengthening and weakening of synaptic connections that

already exist. Then, and much more slowly – over days, weeks and months – new synaptic connections are formed.

The design of brain circuits continues to change. The circuits are not only receptive to the results of first experiences, but repeatedly pliable and modifiable by continued experience. Some circuits are remodelled over and over throughout the life span, according to the changes that the organism undergoes.

(Damasio 1995: 112)

The brain is a ‘plastic’ organ. The continuing developmental aspect of its structure can be symbolized as B^d .

In dementia there is usually a loss of neurones and synaptic connections, making it impossible for the brain to carry out its full set of functions (Terry 1992). Some of this occurs slowly, and is a ‘normal’ part of ageing. It probably arises from the accumulation of errors in the reproduction of biological materials over a long period, and chemical processes such as oxidation. The more serious and rapid losses, however, appear to be the consequence of disease or degenerative processes, and these may be symbolized as B_p (brain pathology). So, very crudely, the situation within an individual can be represented thus:

$$\frac{\psi \equiv \mathbf{b}}{(B^d, B_p)}$$

(Any psychological event or state is also a brain event or state, ‘carried’ by a brain whose structure has been determined by both developmental and pathological factors.)

If this view is correct in principle, it shows how the issues related to personhood are also those of brain and body. Here, there is one particularly important point to note. It is that the developmental, epigenetic aspects of brain structure have been grossly neglected in recent biomedical research on dementia; moreover, there is scarcely a hint of interest in this topic in contemporary psychiatry and clinical psychology. Yet neuroscience now suggests that there may be very great differences between human beings in the degree to which nerve architecture has developed as a result of learning and experience. It follows that individuals may vary considerably in the extent to which they are able to withstand processes in the brain that destroy synapses, and hence in their resistance to dementia.

In this kind of way we move towards a ‘neurology of personhood’. All events in human interaction – great and small – have their counterpart at a neurological level. The sense of freedom which Buber associates with I–Thou relating may correspond to a biochemical environment that is particularly conducive to nerve growth. A malignant social psychology may actually be damaging to nerve tissue. Dementia may be induced in part, by the stresses of life. Thus anyone who envisages the effects of care as being ‘purely psychological’, independent of what is happening in the nervous system, is perpetuating the error of Descartes in trying to separate mind from body. Maintaining personhood is both a psychological and a neurological task.

Well-being in dementia

Having dementia does not, in itself, entail a loss of personhood. These pictures show people with a high level of well-being, despite the presence of cognitive impairment.



The late Peter Ashley (pictured front right) in 2010 receiving an honorary degree from University of Worcester for services to dementia advocacy.

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A resident in an Australian care home enjoying time with a staff member, a sleepy rabbit, and her own stuffed rabbit, a constant companion.

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On being a person

Commentary by Jan Dewing

This commentary on the opening chapter is undertaken from a point of scholarly respect for Tom Kitwood, his research and contribution to person-centred caring. This does not mean, however, that I will accept everything he says as a given. Further, I want to raise some questions about his assumptions. Kitwood left an unfinished tableau and it is the responsibility of others to take this forward in a way that is fair and just to the ideas he shared. His ideas, as are all ideas, are a product of their time and influenced by his worldview, including his experiences and the culture he was embedded in. It is unfair to treat Kitwood's definition of personhood in a rigid or simplistic way, just as it is unfair to accept it as written in tablet of stone for evermore. A benefit of his definition is that it is written in relatively plain English, and has an instinctive appeal to many people. Yet beneath the surface there are several complex philosophical ideas that need closer examination. Had Kitwood been able to progress his theoretical development further, he would have at least clarified his understanding in the light of critique or even refined and progressed it beyond its current form. Instead, contemporary researchers and scholars have done much to both critique and advance the ideas underpinning Kitwood's notion of person, personhood and also person-centredness. Kitwood, though theoretically active, did not leave a large volume of philosophically based work for those following him to draw on and this has been challenging in terms of trying to isolate the philosophical foundations of his work. At best he had an eclectic approach in which he mixed several philosophical ideas together. Perhaps he was eclectic and less formal in his scholarship as he wanted to bring 'academic' and 'therapeutic' psychology closer together. Indeed, Kitwood can be credited with bringing the notion of personhood to life (i.e. for it to have relevance and meaning) for many people concerned with dementia care. It is, however, worth bearing in mind two important points. First, personhood has been a topic of debate in philosophy for many hundreds of years. Kitwood did not invent it per se; instead he brought it to life in dementia care. Second, he laid the groundwork for much of his ideas and his positioning of them in *Dementia Reconsidered* in an earlier non-dementia specific text, *Concepts in Developmental Psychology. Concern for Others: A New Psychology of Conscience and Morality* (Kitwood 1990a). This is a text that, in my view, is largely and wrongly ignored. Two of the challenges in critiquing and advancing Kitwood's scholarship have been the lack of explicit scholarship and the associated lack of a clear reference audit trail in his work (Dewing 2008). In this commentary, I will offer a critique of the main ideas underpinning Chapter 1, discussing them in the context of related philosophical concepts, and finally

consider what the dementia care community needs to address as we move forward with our scholarly, practice-based understandings of person-centredness.

Revisiting core concepts

Many readers of *Dementia Reconsidered* will perhaps recall that the book starts with a chapter on celebrating what Kitwood referred to as 'our common ground' (p. 6). This was unusual at the time, as most books on dementia began with a chapter on the biomedical condition with the text focused on what persons 'suffering' from dementia could no longer do. Further, such chapters mostly presented a negative scenario about dementia, where the experience of those living with dementia was left out entirely or sometimes presented as a 'case study'. Sadly, this often remains the case today, with many textbooks continuing to emphasize abnormality, loss and dependency. Kitwood started his book differently as his intention was to set about challenging readers to examine deeply their values and beliefs, many of which were taken for granted and originating from biomedical science. He wanted readers to take a long, hard look at what and who someone with dementia was, and still is, in terms of humanity. He intended to show that 'they' are 'us' and 'we' are 'them', and any contrived separation was artificial. Kitwood (p. 11) considered the exclusion of persons with dementia from the world of persons as attracting a particular type of inhumanity; he had by then already framed this as malignant social psychology (Kitwood 1990b). Of particular relevance to this chapter is that Kitwood considers the origins of the separation to be from the collective unconscious. There exists, he claimed, a deep-rooted anxiety about, first, ageing and the associated frailty and ultimately a prolonged dying process and, second, about mental instability and moving into a state of 'unbeing' (p. 11). Twenty years on, it can still be argued these two anxieties remain despite much progress in the fields of dementia care and end-of-life care. We can also debate if persons with dementia do move into a state of 'unbeing'. Our values and beliefs and philosophical leaning(s) can assist us to explore this profound concern. For example, it is possible to argue that persons living with dementia do indeed experience an unravelling of identity, which can impact on personhood. One alternative is that it can be argued that persons living with dementia move into a new way of being.

Understanding what a person is, and how we position our definition in relation to what a human being is, must be the starting point for a discussion about what makes a person. In seeking to understand this, we quickly encounter the notion of personhood. Such philosophical and theoretical discussion might appear at first glance to seem far removed from person-centred care. Kitwood makes it clear (p. 7) that a person is not the same as or synonymous with being a human being. A critical question to begin with is to ask why he does this. Given his moral and theological background, it seems more likely he would have opted for the path that claims all human beings are persons by way of some transcendental and non-material means. Taking that route would have significantly reduced the need to have inclusion criteria for personhood. Because he instead highlights the distinction, he then must name and argue criteria that are necessary and sufficient for human beings to be considered as persons. As anyone who has tried to account for this, a criterion-based view of personhood soon becomes fraught with complexities. At the start of Chapter 1, Kitwood (p. 6) stresses that we 'have to recognize men and women who have dementia in their full humanity'. To achieve this, Kitwood argues it is helpful to be concerned with (i) the uniqueness of persons including embodiment, (ii) the category of personhood and (iii) the centrality of [a particular type of] relationship (pp. 6–7, 11). The key features underpinning this are discussed below.

'Personhood' is the central idea to Chapter 1 of the book and Kitwood defines it as 'a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being' (p. 7). There are connections here to the ideas expressed by Buber (1878–1965) and Levinas (1906–1995). For Buber, the I–Thou relationship is between two subjects in a relationship that affirms the 'other' through the act of choosing to relate in a particular way (Jewell 2011). An important point is that the way of relating is not dependent on roles, power or organizational status. This idea suited Kitwood as his intention was to downplay the dementia and to see the person first and foremost. Similarly, he intended that caregivers should see their own personhood and not be constrained or shaped by the culture of the organization or role they were in. To a greater extent it is the former that has received most attention within dementia care and the latter notion has been somewhat reduced in its significance, which in my view has delayed progress. I would contend that person-centredness is primarily about culture, one that holds and enables person-centred care to take place within the overall culture (Dewing and McCormack 2017). Person-centred care requires a person-centred culture to be present and working effectively. Therefore, we will make the most progress when we approach person-centredness as a culture (McCormack and McCance 2017) not just in terms of its being a relationship between individuals.

While Dennett (1976) considers there are seven layers of personhood and Smith (2010) outlines some 30 causal capacities necessary for subjective and objective activity, Kitwood avoided the pitfall of setting out personhood in relation to causal capabilities (for example, cognition, decision making, agency, and so on). Instead, he positioned it as an attribute of moral relationships between human beings. This is often referred to as a relational conceptualization of personhood, according to Buetow (2016). We are helped in our understanding about what Kitwood was hoping to convey when we recognize and appreciate some of the philosophical ideas that he was influenced by. I have already noted the influence of Buber (to whom he devotes two pages); he also cites Descartes (1596–1650) and Kant (1724–1804), as well as contemporaries such as Post (1951–). Kitwood's concern for others was such that he spelled out, specifically for dementia care, the deeper moral implications of actions and inactions people could take in their caring roles. Kitwood, however, departs from Buber's position on personhood, defining it as a gift rather than a moral entitlement. The definition offered here is highly westernized (Callegaro 2013). In contrast, for many Indigenous human beings, such as Australians (McMillan et al. 2010), personhood is connected to community and to country. Similarly, in South Africa there is a word 'ubuntu' (or unhu), meaning 'humanity' or 'humanity towards others'. Ubuntu can be used in a more philosophical sense to mean a belief in a universal bond of sharing that connects all humanity. The connectedness is fundamentally about moral goodness and moral beauty (Ikuenobe 2016). At its core, ubuntu asserts that society, rather than any individuality, gives human beings their humanity or personhood and I think quite effectively captures the essence of Kitwood's definition (i.e. the bestowing of personhood). Eze (2010) suggests that, through recognition of an 'other' in his or her uniqueness and difference, we also validate our own personhood. Interestingly, Eze considers this position as an ideal, although also contends that humanity is a quality we owe to one another.

In the first chapter, Kitwood primarily attempts to consider the ethical, social-psychological and neurological significance of personhood from a westernized perspective – an enormously ambitious aim for the opening chapter. Because of this, there is an oversimplification of complex concepts and a tendency for these to be presented in a linear fashion. Kitwood's definition has several major limitations. For example, he defines personhood as being

bestowed or gifted by one human being to another. We might ask: Can, and should, anyone of us bestow personhood on another person? What happens to others and to our own being, should we withhold it? The standing or status is viewed within the context of society and relationship, although the nature or type of relationship is not clarified, other than one that has recognition, respect and trust (p. 7). These attributes are part of a person-centred relationship, but not the totality of it. To go beyond this in the text, in terms of clarifying core concepts, is challenging and requires a large degree of interpretation. For example, Baldwin et al. (2007: 180), inaccurately in my view, argue that Kitwood intends for personhood to be bestowed by others on the person with dementia and not the other way around. In other words, that this is not a mutual relationship. It may be that focusing too much on the definition is misguided. From my reading of the different sections of the chapter, a number of key concepts, as described below, stand out and seem to be of (more) significance for considering and defining more creatively and inclusively what constitutes personhood.

Unity of all human beings

Post (2000) helpfully refers to this as moral solidarity. He argues for a morality based on what all humans have in common with one another, rather than on what our differences are. Central to his argument is his challenge to the western value of 'hyper-cognition' – in other words, that the most important features are clarity of thought and mind (Post 2006). Particularly at this time, when many countries are highlighting the growing cost to national budgets of ageing populations, it becomes too easy for people with dementia to be 'scapegoated' by wider society because of their disability and decreasing utility. Kitwood suggested that intellectualism and individualism are two significant western cultural factors that have led to people living with dementia being regarded as lesser or non-persons. Intellectualism is underpinned by cognitive capacity and capabilities, and individualism by autonomy and agency (Higgs and Gilleard 2016). The more we include items or categories of intellectualism (see, for example, Smith 2010) and attributes associated with individualism (see, for example, Torchia 2008), the further we marginalize and then exclude persons with dementia, and indeed many other persons. Yet Kitwood (1993) reminds us that as we make the effort to discover the person with dementia, we also discover something of who we are. I suggest this can be viewed as a living meeting between two or more persons, in much the way Levinas (1985) proposed.

Inclusion

Kitwood contended that personhood should be conceptualized more broadly, where personal and social relationships and moral solidarity are the foundational principles, not capabilities. Therefore, he specifically identified inclusion as a precondition for relationships, and ultimately for personhood. Inclusion here can be thought of as an active process.

Relationship

Buber (1970) proposed two types of ways that people relate to one another: 'I-It' and 'I-Thou'. The I-It way of relating is one in which a person relates to the other in a distanced, non-involved way that does not fully recognize the individuality of the other, and consequently the other becomes less of a person and is even objectified. In contrast, the I-Thou way of

relating involves meeting the other person in a genuine human exchange. Kitwood stresses that I–It relating never moves beyond the banal and trivial (p. 9), while in I–Thou relating, there is an authentic engagement and he quotes Buber, who says ‘that all real living is meeting’ (1937: 11). For Levinas, the first responsibility of philosophy was that of an ethical duty to the other, rather than exploration of knowledge. Levinas maintains that the encounter with others is our primary and privileged responsibility, and it is through this ethical priority that ‘I’ gets to become me. This line is very similar to that of Buber, although Levinas probably stresses respect and relationship more than mutuality and dialogue as Buber does. Further, Buber’s I–Thou relationship is explicitly set up in the image of an I–Thou relationship with a Judeo-Christian God. Kitwood does not reflect on this issue further, either within this chapter or the rest of the book.

Uniqueness of persons

Scruton (2017) considers this as the sense of ‘I’ and ‘me’ unique to humans. Kitwood may be drawing on Kant’s idea that persons have unique value, often called dignity. Kant conceives of dignity as meaning that persons are both infinitely valuable and irreplaceably valuable. Zagzebski (2001) argues that persons are infinitely valuable in relation to shareable qualities of their human nature, whereas they are irreplaceably valuable because of other aspects of personhood such as personality; and, as Harees (2012) says, are situated within distinctly different self-reflective and imaginative biographies. The uniqueness of persons can therefore be situated within the individual or within a community or culture, within capabilities or within attributes of the relationship between humans. Depending on our values and how we understand the uniqueness of person, it will shape how we facilitate the development of person-centredness, and how we organize, deliver and evaluate person-centred care. We can see in his work how Kitwood considered personality and biography as core to the person coming first.

Embodiment

Kitwood did use this term in his writing of *Dementia Reconsidered*. However, he used it in a very limited way. He referred to it mostly to mean the neurological and mental effects of a condition or experience on the physical body and general health. He did, though, consider sentience in more depth in his writing. Briefly, sentience is the capacity to feel, perceive or experience subjectively and is different from reason (the capability to think in a certain way). Possibly, as a psychologist he tended to privilege the mind and clearly positioned his ideas within a Cartesian model of mind/body duality. By moving away from consciousness and the mind/brain, and beyond the duality to the body and embodiment, we can open up some new possibilities for inclusiveness in how we define personhood. Matthews (2006) nicely emphasizes that our existence (i.e. consciousness) as a person emerges from our bodies not simply from the mind. Kontos and Martin (2013) have further explored ‘self-hood’ in relation to embodied dimensions and conclude that inclusion of embodiment can encourage innovative care practices. Kontos argues that embodiment disentangles personhood from the cognitive categories upon which it is presumed to depend. Similarly, Lindemann (2014) proposes a view of personhood as the bodily expression of the feelings, thoughts, desires and intentions that constitute a human personality, as recognized by others. Others then respond, in certain ways, to what they see. Because personhood is a social practice,

the author argues that others can sustain personhood when we can no longer practise it ourselves.

Moving on

The popularization of Kitwood's definition of personhood has masked his overall purpose, which is a 'moral concern for all others' (Dewing 2008: 10). This moral focus is consistent with his emphasis on relational personhood and therefore on his use of Buber's philosophical ideas (I–Thou). When persons meet in an authentic I–Thou way, they potentially perceive and experience the world differently. In the space of the meeting and living there exists a potential for personhood, of each, to be maintained or enhanced. Kitwood's moral intent is to the removing of any artificial separation among humans. Further, he strongly rejects any criterion based on cognitively derived intelligence, including rationality, and bemoans the minor part emotion and feeling have in the scheme (p. 8) saying:

People who have dementia, for whom the life of the emotions is often intense, and without the ordinary forms of inhibition, may have something important to teach the rest of humankind.

(p. 5)

It is essential that those of us with intact cognition recognize that life can be and is lived by people like 'me' and 'you' in a different way or ways. Perhaps, when we consider the living through or beyond dementia (Swaffer 2016) we are looking at a radical form of diversity in the evolution of humankind that we need to account for in a united moral and inclusive way. Taylor (2011) says that 'you' and 'I' are fundamentally different from one another in ways that we probably can't express or perceive and appreciate. Central to Taylor's comment is that even if our brains are different, each of us is still as complete as we can be and therefore a *full* human being or person.

It is hard to escape thinking about personhood as not depending on brain or mind consciousness, memory, self-hood along with ideas of decision making, agency and autonomy. Yet this is exactly what we need to do in order to open up new representations of personhood for people living with dementia. Human beings with dementia are persons, in both fundamentally the same way and yet, at the same time, in different ways than they were before. Based on the discussion in this chapter we perhaps need to re-begin our re-considerations of personhood by including these concepts:

- A body consciousness
- Moral entitlement not a gift
- Dignity
- Always being open to difference, diversity and becoming.

As we move forward, the explorations we have must be inclusive of persons living with or beyond dementia (Swaffer 2016) – at present many persons living with dementia are still (kept) on the periphery of these scholarly discussions. Each time a new definition of personhood is released we, intentionally or unintentionally, position personhood within philosophy that is either a moral or a metaphysical category (Higgs and Gilleard 2016). While the nature

of personal identity and 'self' occupies metaphysics, in moral philosophy the term is concerned more with the moral standing of persons. Both psychiatry and psychology have approached personhood and dementia in metaphysical terms, while the law and theology, on the other hand, have been more involved with moral considerations of personhood as 'a foundational concept in many systems of ethics' (Higgs and Gilleard 2016).

Summary

Revisiting Kitwood's ideas and his definition 20 years on, I conclude that he did advance the theory of person-centred dementia care and also influenced the development of person-centredness more broadly within the UK countries and beyond. It remains the case that Kitwood presented a definition of personhood that continues to be influential, despite its theoretical inconsistencies. The premise that personhood can be an optional gift is not a robust notion, even if it is the way it can happen in the real world. Maybe it is time we stopped searching for some special definition of personhood for human beings living with dementia and, in the desire to achieve unity and inclusion, instead perhaps look, alongside persons living with dementia, to more general considerations of personhood that capture our shared humanity, whatever way is our individual or collective being in the world.

Reflection points

- How would you summarize the progression of philosophical ideas since Kitwood's definition emerged?
- What might the next 10–20 years bring in terms of challenging our ideas on human-based personhood?
- How would you argue the call for a universal definition of personhood that is inclusive of persons living with dementia (but not specific to people with dementia)?