Songs without Words - learning a language of dementia

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My mother is 90. The first signs of what turned out to be dementia emerged some five or six years ago – the usual memory lapses and slight confusion.

At the time, I simply assumed that, like her mother and aunt before her, she was 'going senile', that there was nothing to be done beyond taking care of her as best we could, and that she would simply become more forgetful and confused. It was only with the discovery of the Alzheimers Society that I began to learn that this was a disease: that it had causes, or at least the symptoms were caused by specific physical changes in the brain; that there were likely to be somewhat predictable stages of the disease; that there were drugs available to slow its progress; that there were different types of residential accommodation appropriate to the care of elderly people with dementia; that there were many resources with the help of which it is possible to respond to people whose brains are changing, and so on. It was a steep learning curve. Often, it seems in retrospect, each time I discovered some new information it was already becoming irrelevant, as my mother was by then moving on into a different stage.

So, as she became silent, unmoving, more and more drawn in on herself physically, (coincidentally or not after being sedated for a period of weeks), I simply 'did my best' – attempting to communicate, to engage with her. I would sit with her. I would say simple things. I would stroke her face, her hand. No response: she continued to stare ahead as if I were not there. I visited less often; I timed my visits to coincide with meal times so that I could at least feed her. But I felt very disconcerted: sometimes rejected, certainly useless. I came to believe that my mother was *unable* to respond at all, that her brain was so clogged with plaques and tangles that there *was* no activity. There were, after all, plenty of other people in her nursing home who sat all day staring into space, looking vacant, silent, unmoving, like her. This must be 'normal', this must be the inevitable end to which people with severe dementia came. And yet I could not quite let go the possibility that there were things going on because of the occasional word or phrase that emerged out of the blue. Also I had noticed that any slight sign from my mother nearly always came just as I was leaving: it was as though she was telling me 'Don't go' or 'This is not the end' or 'Don't leave me'. On the other hand I had not come across anything to suggest that people in this late, silent stage of the disease can be contacted in any meaningful way so assumed that along with all the other people in the nursing home who sat or lay silent and staring this was normal.

A friend, who is also a therapist using Process Oriented Psychology, told me about the weekend course on 'coma work'. It mentioned people in coma or coma-like states, including dementia. It spoke of withdrawal. I still was unsure that it could help my mother. Was she not *unable* rather than withdrawn? But I had to give it a try. I went on the course. I left it feeling fairly neutral about it, neither expecting great things nor expecting the approach to fail. I would see. What I had taken from the course was the very simple notion that I needed to look for any signs of activity from my mother and support her to express those to their fullest. (There is much more detail and sophistication possible but that is not my focus.)

The effects were startling. On the first occasion that I tried this method with my mother, she moved her hands and arms a lot and in quite big gestures. She made sounds. She spoke clearly, firmly and with complete precision, from time to time. When I was leaving and I said 'Goodbye for now', she replied 'Goodbye for now' and, after a little pause, 'You *are* kind'. I will never forget that moment. It took my breath away. Since that time, and I am writing about six months after the course, we nearly always have some form of connection, of communication when I spend time with her. Sometimes she doesn't make any response, but that is easier because I can recognise that she is *choosing* to ignore me for whatever reasons, and I feel fine about that. She has precious little choice in her life and is almost entirely a recipient and passive. If she is making a choice then that seems to me very valuable and not to be discouraged.

I will attempt to give a picture of how my mother and I between us have interpreted coma work to our benefit.

On arriving in my mother's room, I settle myself very close beside her in such a way that I can speak into her ear and at the same time have my finger tips on her wrist, at least to start with. Usually this entails me kneeling to one side of her reclining chair or her bed. I don't expect any contact from her at this stage, though very occasionally she turns to me. Next I check carefully what activity my mother is already engaged in. She may, for example be looking, or chewing (she does that a lot), or moving one finger a tiny bit. She may be moving her facial muscles or even a foot. She might sigh. Any tiny event is important. I will then choose to focus on one of these, to start with at least, the one that seems to me the most energetic or striking. With my voice and sometimes also with my hand (or just a finger) I will support my mother to 'go with' that little impulse, to give it its fullest expression. Always I am following her lead, never suggesting or initiating. Typically, in the time since we began this, I will find myself commenting encouragingly on her looking/ seeing: 'yes, you have a good look', 'oh that looks interesting/ upsetting/ amazing' (depending on her expression as she looks), and so on. Or I encourage her chewing, with 'that's good, you really chew it', or, if my intuition prompts me thus, 'that's fine, you chew it over'. And almost all of the meetings we have are now spent with my index finger and her thumb in a constant 'dance': pressure from her thumb is replied to with the same pressure from my finger at the same speed. Sometimes the dance is slowish and soft, other times it is firm, insistent, other times very pressing. And all the time I am encouraging this activity with my voice/words: 'What an energetic/ busy/strong finger!', 'This is lovely, our fingers talking'. A few times, her whole hand starts to move away from her body, where it is usually held tightly, and around in the air; I simply keep, literally, in touch as she does this, while also speaking my interest and encouragement. And once or twice she has seemed to be pushing, so I offer my palm held against her fist (her hands are most often in fists), with as much firmness as she is pushing, so that she has something to push against.

On one occasion, even before I got down beside her chair, she looked up at me and said 'hello darling'. Another time, she suddenly turned and looked straight into my face and stayed looking and looking and looking, like a baby does. Just recently she lifted her head a little off the pillow at the same pulling my hand: sensing her intention, I moved my face right close to her and she kissed me. She 'speaks' much more often, sometimes words, the occasional phrase, sometimes sounds. Our finger meetings are sometimes like little waves on a smooth sandy beach in calm weather – a very gentle to and fro, with my voice and occasionally hers also 'conversing'. Very interestingly, when I remark on her chewing, albeit encouragingly, she often stops; and a few times she has taken my finger to her lips then into her mouth and given it a good chew! My understanding is that biting and chewing are expressions of aggression, by which I simply mean energy which wants to go and do something 'out there'. So it seems to me much more healthy for my mother to be biting something other than herself: she is thus making an impact on the world, at least her little bit of it, making a difference. And there have been times when she is quite angry and at her most vocal: she may bite the spout of her beaker and make a face which I recognise as exasperation, while also pushing with her hand vigorously. Sometimes she smiles and looks very accepting.

From the vantage point of several months since first using this approach with my mother, it now seems blindingly obvious. I had been trying, unsuccessfully to communicate *to* my mother. Now I am seeking to help *her* to communicate outwards: to whomever/whatever. The fact that she cannot speak (to all intents and purposes), merely means that she is largely *post*-verbal. She does, it turns out when I really pay attention, have several ways of expressing herself. And the miracle is that in so doing she is once again engaging with me, sometimes very directly and purposefully. Which in turn means that I have been able to respond to her, again not primarily using words, or at least very few, though voice tone is important. As far as I knew I was simply attempting to encourage my mother to express herself, a worthwhile end in itself of course. In the event, so much else has happened which I thought would never happen again.

I am struck by a number of things about this whole process, this journey of discovery. What sums it up is the question as to how I came to not know what I know, in this context.

In my working life I am a psychotherapist, and it is second nature to me to pay attention to everything that my patients do, not just to what they say. Things like the shaking of a head while a person is saying 'yes', a constant scratching at oneself, a foot held in tension, eyes moving rapidly – all these unaware activities I believe may offer clues about hidden impulses, denied memories, disallowed thoughts. It simply had not occurred to me to give the same attention to the tiny glimpses of my mother's interior life that were and are available, the tips of her icebergs. I can now recognise that she is simply post verbal and that we can communicate without words at least to an acceptable degree, and sometimes in a way that is quite beautiful, even awesome. Words such as communion, intimacy, Love are wholly appropriate.

I see now how, as she ceased to be able to speak in the ways she always had, her main medium of communicating deserted her. I remember her often starting to say something, hesitating, trying again, then actually saying 'Oh I can't say it, I won't bother'. I imagine that she began then to retreat inside herself and perhaps understand herself alright and then, maybe, not even be able to do that. I don't know. But certainly, it never really occurred to me that we could find alternative ways of communicating, beyond holding hands. And what certainly didn't figure for me was to find any way to help *her* to express herself. I simply tried harder and harder to express myself to her: completely one way as I now recognise. And I see that in other people who engage with her; for the most part they speak *to* her, hoping she will receive/understand them. It is so obvious now and so simple and so profound: we need only help my mother and all those in her condition to 'say' what they want to 'say' and they will then 'speak' with us, and maybe 'hear' us, engage with us.

One answer to my question as to how I could not see this is a personal one: from being a girl I learned that I had to help my mother and in particular to help her communicate with my father. So it is my default position. My activity in the face of her passivity is deeply ingrained. But what compounded this position, would not support me to climb out of my rut and have a look around, is the current assumption that elderly people with severe dementia *are* incapable of communicating or have nothing *to* communicate. I say current assumption and I am speaking of, probably, the vast majority of so called dementia care in this country. I want to be clear that there are notable and wonderful exceptions that I read and hear about as I discover more and more about this awful yet also fascinating process of brain change. It is very exciting to hear about people who are promoting care which *understands* dementia, the person behind the disease, therefore ways of being with such persons and of assisting them to have good, satisfying, rounded lives – without patronising them. But much of what I have witnessed as I have spent time in care and nursing homes has been about fitting people into a package, into a way of living that is borrowed from the lives of people without dementia, and indeed from an old fashioned idea of the (nursing) home as a place where people need care as though they had just given birth or were recovering from an operation in the 1940s or 1950s. At that time, I think it is a fair generalisation that it was not widely accepted that emotional, psychological well- being had a huge impact on physical recovery. The assumption was that as little activity as possible was the best way to heal. And very powerfully it draws on a largely medical model of giver (by experts) and receiver (by obedient patient) of care.

Such little ideas as providing 'finger foods' when someone is no longer able to use cutlery, so as to prolong independence and dignity, are heart warming to me. As is the notion of 'prompted voiding': many people with dementia need not become incontinent if someone who was familiar with their regular times of going to the loo reminded them and helped them to find their way. Incontinence is often nothing to do with failure of bladder muscles and everything to do with not thinking ahead and not remembering where the loo is and – amazingly – staff being unwilling to escort a sufferer to the loo because it doesn't fit in with what is on the timetable.

I use these small and intimate, basic examples to indicate how a true understanding of dementia can provide an alternative to the culture of passivity, dependence, helplessness which is the lot of many sufferers. And in the field of communication, I look forward to the time when it is the norm for carers and others around people with dementia automatically to assume that the person does have things to 'say' and that it is up to them to find ways of 'hearing'.

I don't think it is an accident that I spend my time with my mother on my knees. Our time together is out of the ordinary. It is suggested that people with dementia, far from being insensate, are more than usually intuitive and receptive to mood and emotion. Certainly I am experiencing that connection which, being largely wordless, is more direct and deep and immediate than she and I would probably be having if our old, conventional conversations were happening. Together now we often go to the heart of things; and that is immensely precious.

Further Reading

Shenk, David. The Forgetting: Understanding Alzheimer's - A Biography of a Disease. Harper Collins, London 2003.