

'Curing Dementia':

Medical possibility or political rhetoric?

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Talking of 'curing' dementia can seriously distract us from the very difficult – yet humbly rewarding – tasks of pastoral care that are bound to increase.

'David Cameron has said he wants dementia cured by 2025'

Daily Telegraph, 11/4/15

Of course, politicians must continually and publicly ply not just concern, but visions of positive assertion. A campaign trail intensifies the appetite and supply.

We can all share their aspirations: a world of unified peace, security and fulfilment – thus absolved of cruelty, poverty, injustice, accident or poor fate. Such fundamentals receive little contention. But next come tricky questions: what is really possible? and how?

Cameron's election-primed optimism may be well intended but it is demotic: such questions quickly expose its grandiosity and flimsiness. Yet there was no public challenge to this specious rhetoric. This collusion is notable: it tells us much about ourselves and our follies, and is thus worth exploring.

It may be that we wish to deny a more probable truth that is more sobering. For despite enormous resources, efforts and research, the vast bulk of dementia remains incurable: yes, we can certainly reduce some contributory risk factors and provide our best technical and human support, comfort and containment – but these are very different from a common 'cure'.

So, while we are duty-bound to search for very elusive cures and, more confidently, to counter the known social and physical risk factors, we must also brace ourselves for an unpalatable likelihood: many of us will succumb to dementia. This is due to the fact that mostly (though certainly not entirely) dementia is age-related. It is also true that the longer we live the more likely the general degenerative failure of our organs and skeletal frame. The brain is our 'organ of self', so when this is a solitary herald of decline, the poignancy is especially painful.

Some aspects of our decline we can parry, but then we should count our blessings. Yes, we are living longer and – if we are fortunate – we may have

many late years of gratified and active life and engagement, before a sudden or rapid death: an 'ideal' old age and end of life, many may think. What is much more common though is much less ideal – decline that is diffuse and incremental: the slow erosion of our autonomous functions, pleasures, powers and agency. So, modern medicine offers us a mixed blessing: we are granted added years, but often with an inescapable tax – the painful ebbing of our self and life. And while technology may alleviate some of that tax, overall it will increase. Dementia will be central to much of that pathos.

Decline and die we must: so what is the best way?

Our current medically modelled approaches often avoid these questions at great economic (and sometimes human) cost. For example, we are currently launching Dementia Clinics: these function by formulaic fusillades of very expensive brain scans, prolix and jargoned Clinical Psychology reports, 'full screen' blood tests – almost always these provide much data about the largely ineluctable: we are still left with the human problem of our disintegration of self. Similarly, medication is likely to serve largely as a placebo for both doctor and patient. Such technology-based, problem-solving activities – iconic of David Cameron's mooted 'cure' – is certainly what the NHS is generally better at, for example providing coronary artery or cataract surgery. Yet dementia – our loss of self and sentient relationships – mostly lies beyond any such power for biological engineering.

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When fate and fortune are running against us, and technology can take no decisive role, what do we then need from our kin and professionals?

We need skilled comfort and guidance. We need bonds of familiarity and affection that can then both witness and understand our experience and our stories. Without these kinds of encounters there can be little meaningful palliation and containment. When we are able to approach people in these personal ways we can then offer them our best *pastoral* healthcare. But without such personal suffusion the bonds between carer and sufferer

degrade to the alienated and frustrated. There is a simple principle that needs space and protection: the more you see of someone, the more of someone you see.

Such principles used to be the well-established foundations for our better personal medical practice. Yet it is here, at the heart of pastoral healthcare, that we are now increasingly failing. We have done this inadvertently, but by selective neglect: by investing our resources – both economic and human – almost entirely into technology-based, disease-centred systems. This then relegates our more nuanced personal and vocational activities to become, first, peripheral and then unviable. Personal doctoring becomes pushed aside by public health.

What does this mean? It has led to a health service where everyone can have shared data, but personal knowledge and understanding are increasingly hard to find. It is a world of overwhelmed administrative signalling but sparse personal communication; where the practitioner knows the statistics but not the lives; where there is an 'efficient' rota of Care-Coordinators, but the vulnerable patient and their family does not know the name of their doctor. In such conditions how can we offer imaginative and nuanced personal care – the kind we need in our decline?

The institutional trends in the last two decades have proved inimical to our better pastoral healthcare and practitioner morale. The stern thralldom to ever-increasing specialisation, measurement, data, goals and targets, formulaic regulation and monitoring – all coordinated by larger and remote bodies, often themselves in a state of conflict – leaves almost no head or heart-space for mutually gratifying personal care.

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It is unlikely we will be able to cure most dementia, but our responsibilities of care will grow enormously. Cameron's blithe short-circuiting of this does us a great disservice, as have so many services modelled on similar assumptions.

Our recent healthcare's mammoth (mis)constructions have had much investment: demolition will not be easy. What can we feasibly do to invest in the best of our care for one another? Here are some preliminary suggestions:

1. Restore the universality of personal lists to GPs. (The Health Secretary's recent corrective initiative is too restricted to be adequate.)
2. Encourage smaller GP practices. (Relationships and personal identifications are often better on a smaller scale.)
3. Encourage established GP Principals, not locums or salaried Assistants. (Much as above; longer-term commitment often widens and deepens human interest and identification.)
4. Restore General Physicians in hospitals. (General Physicians could deal with the majority of complaints, referring to a tertiary specialist only severe, unusual or obscurely intractable complaints. This would enable the growing number of elderly frail patients with multiple co-morbidities to make better personal bonds with a particular hospital physician and his team.)
5. Restore Consultant-led Firms who have designated Wards. (As with the previous suggestions this would facilitate personal understandings, bonds and investments.)
6. Apply these principles to Mental Health (eg restore General Consultant Psychiatrist-led Firms who are also responsible for their designated In-Patient facilities).

There are many other 'minor' examples that one can add. Here is a last one, but more fundamental:

7. Abolish the Internal Market, Financially-based Commissioning, Purchaser/Provider Splits and autarkic NHS Trusts.

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Technology and managed systems often eclipse our complex human difficulties and thus engage poorly with them. It is in these areas that we require a different kind of patience and attention.

In my first two decades of NHS practice I was privileged to have good mentors to introduce me to the spirit and skills of pastoral healthcare, and then a supportive milieu that encouraged me to develop these.

In the last twenty years that gentle tide has accelerated with great force in the opposite direction: there is now very little space left for the autonomous engagement of heads and hearts. As my healthcare colleagues have become ratcheted by ever-more complex and prolific technologies and systems of governance, so they have become increasingly estranged from the invaluable and delicate vagaries that make us human.

This cultural loss in healthcare forebodes my own fears and inevitable vulnerability. As my own ageing becomes more evident, the distinction between cure and care becomes more pertinent. When my turn comes to depend on the care of others, I hope they will have the time, imagination and interest to attend the personal as well as the technical; to take humble pride in tending the human fragility that uniquely burgeons and blossoms, and then fades and dies.

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