My mother died on 22 May at age 86. She had Alzheimer’s disease, congestive heart failure, and probably a small stroke at the end. She fell twice in her last year, causing two debilitating fractures.

In caring for her and arranging for her care I learnt a lot that I should have already known.

The lessons began after my father died eight years ago. It took a year or so, after some financial decisions had worked to her disadvantage, for my sister and me to realise that my mother was not really capable of managing her fiscal affairs. The lesson here was not her inability; rather, it was the vital and complementary contributions of life partners. She helped my father through his declining health, and he kept track of the finances.

Although I spend a lot of time railing about the crazy US healthcare system, I never got an up-close, personal view of what our elderly have to deal with until 2007. I told my mother then that I’d be happy to go online and pick a prescription drug plan for her. I got a list of her drugs and logged on to www.Medicare.gov. OMG (as our kids would text), it was unbelievably complex. There were dozens of plans to choose from, each with different deductibles and copayment rules; each with payment schedules for her drugs; and each with different rules for the dread “doughnut hole” of no coverage. It was a nightmare. Here I was, a doctor with decent computer skills, and I was baffled. What were they thinking when they designed this?

I also learnt from my mother what a sad, cruel disease Alzheimer’s is. She did not even have severe Alzheimer’s, but she lost her short-term memory. This made it very difficult to be around her, as she was constantly asking the same questions over and over and over. She called us multiple times during the day and night repeating a question or concern. We were often angry at her, and (more importantly) she was always anxious.

Her Alzheimer’s also meant that she was constantly disoriented in her final round of transfers to hospital, rehabilitation, assisted living, and back to hospital again. She usually had no idea where she was or why. What I learnt from this was not how Alzheimer’s affects individuals; rather it was how poorly institutions (especially acute care hospitals) do at informing staff about patients’ disabilities. Time and again I would ask a new doctor or nurse—who had previously reviewed her chart—how my mother was doing. They would reply “she’s confused today,” or “she’s not a very good historian.” Well, of course she’s not a very good historian, she has bloody Alzheimer’s disease!

My mother’s last year demonstrated once again how dangerous falls can be to the wellbeing of elderly people with reduced vision, agility, and bone mineral density. Her first fall, resulting in a fractured pelvis, slowed her down for a while, though she was soon walking with a walker and participating in her usual activities. Her second fall caused a comminuted femur fracture. It was the initiating event in the downward spiral ending in her death.

Another important lesson was how difficult it is to ensure continuity of care across multiple care settings. She would be discharged from hospital on one dosage of diuretics for her heart failure. Somehow, when she got to her long term care facility, despite correct transfer orders and an intrusive doctor for a son, her meds got confused and she received too little medicine, resulting in reaccumulation of fluid and readmission to hospital. The lesson? Not that individuals were at fault, but that systems failed to protect her.

None of this is to say that she did not benefit from the hard work and kindness of many caring professionals. She did. But it is not fun and not very rewarding (in either an emotional or financial sense) to work in long term care. It is a big challenge to recruit, train, and motivate people to do nursing assistant work. In the US at least, we have a huge nursing shortage that is obvious to anyone who has a family member in an acute or chronic care setting.

The final lesson my mother taught me was about end of life care. It was very hard for me, as the family doctor in both senses of the term, to figure out how much care was enough. The parade of specialists assured us they could fix her individual problems—tap her pleural effusion, diurese her oedema, bypass her feeding problems with a tube. The real question, of course, was not whether they could do any or all of these things, but whether they should. Would it help her symptomatically or lead to a meaningful recovery?

In the end, she died peacefully, and we think comfortably, of no particular problem, or perhaps from all of them. I learnt from my mother when the end had come, and of course so much more.

Thanks, Mom. God bless.

Douglas Kamerow chief scientist, RTI International, and associate editor, BMJ. dkamerow@rti.org

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Crocodile tears for health inequality

Why are academics and others who have participated in documenting health inequalities not campaigning vociferously for more progressive taxation in the UK?

I begin to feel that I have witnessed one too many worthy presentations on the nature, extent, and dimensions of health inequality—locally, nationally, and globally. I have myself been guilty of such presentations in the past, but almost no one needs to be told about this any more or to be asked to look at more graphs or tables of figures. Instead, we need finally to find the collective will to do something about it. The documentation and discussion of health inequality has become an industry: a search of Google Scholar reveals 7860 academic references in 0.18 seconds. Like the National Lottery, the scholarly exploration of health inequality seems to result in the paradox of the poor directly subsidising the more affluent. The same process is in action, to a greater or lesser extent, when those struggling to cope with unemployment or inadequate housing are referred for counselling or prescribed antidepressant medication. Again, I have been repeatedly guilty of this and, each time, the distress of poverty provides employment and opportunity for those who are better placed. Where is the social justice in this?

Crocodile tears imply insincerity or even hypocrisy and such a suggestion would be entirely inappropriate for those whose painstaking documentation of health inequalities has put the issue on political agendas across the world. Yet solutions have remained stuck at the level of complacent rhetoric for far too long, the facile assumption being that once health professionals have been properly informed about the extent of health inequalities, they can somehow be expected to reverse them.

In 1967: “How much right have we to go on being always patient on behalf of others?”

It has been much too easy and much too convenient for governments to locate the task of lessening health inequalities within their health services. A search of the Department of Health website finds 279 references to health inequalities and every health professional is now well used to being exhorted to do something about them: as if a brief contact with the health service could compensate for a lifetime of disadvantage and deprivation, with the resulting almost inevitable attenuation of opportunity and hope.

In stark contrast there are only eight references on the website for the Department of Work and Pensions and, most notably, only five for the Treasury.

In act 2 of Antony and Cleopatra, Shakespeare has Mark Antony describe a crocodile as living “by that which nourisheth it.” It is the same with health inequalities, which are directly nourished by the underlying socioeconomic inequalities. However good a health service and however committed its staff, health inequalities will persist if their socioeconomic nourishment remains intact. In its magisterial review for the World Health Organization in 2008, the Commission on Social Determinants of Health made it very clear that health inequalities are a matter of social justice and directly attributable to “social norms, policies, and practices that tolerate or actually promote unfair distribution of and access to power, wealth, and other necessary social resources.” Writing the day after the state of Israel’s murderous defence of its morally indefensible blockade of the Gaza strip, I find it impossible not to reflect on the extent of social injustice so graphically illustrated by the blockade and so predictably reflected in gross health inequalities, particularly for children. Under 5 mortality in Gaza in 2008 was 28 per 1000 compared with 6 in Israel.

All citizens concerned with social justice should be aware and understand the implications of the Gini coefficient for their country and should call their governments to account for their performance against this measure. The values range between 0, in the case of “perfect equality” when everyone gets the same share of income, and 1, in the case of “perfect inequality” when one individual gets all the income and everyone else gets nothing. The Organisation for Economic Cooperation and Development (OECD) publishes the Gini coefficient for a range of countries before the imposition of taxes and other monetary transfers between citizens. As so often, it is instructive to compare the UK and Sweden: before tax, the UK has a Gini coefficient of 0.48, which is reduced to only 0.37 by our government’s fiscal policy, whereas in Sweden a starting Gini coefficient of 0.45 is reduced to 0.24 by taxation and transfers.

Sweden’s policy of progressive taxation is reflected in a society that has prioritised social justice and has been rewarded by much less marked health inequalities.

So why is it that all those academics and others, like me, who participated in and benefited directly from the documentation of health inequalities, are not campaigning vociferously for more progressive taxation in the UK? Could it be because we have a fundamental conflict of interest in that almost all of us, situated on the gaining side of health inequality, would be expected to pay more tax if such a policy was implemented? If this is true, then it really is a case of crocodile tears.

Iona Heath general practitioner, London iona.heath22@yahoo.co.uk

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