

The costs of social care.

Tim Dartington

What are the conditions that would encourage a more compassionate society? The government has been consulting about the future of social care, though you would be forgiven for not knowing about it. The trouble is, social care does not have a very good image. Of course we all pay lip service to the carers in our society, the people who look after the members of their families and sometimes neighbours with disabilities, disease and distress. We thank them for not confronting us with our fears about their vulnerability and therefore our own.

Social care, unlike health care, is means tested. This, despite the report of the Royal Commission that recommended that this distinction was unfair and discriminatory, and the government's own expressed wish for joined up thinking, partnership and integration of services.

Jane, 58, knows about this, having both social work and nursing qualifications and working in the NHS for twenty years. Her mother had been a Labour Councillor, working for as many years in the interests of those who lived in her London borough. We might think they are both contributors to a compassionate society, supporting people when they needed help.

Her mother lived to a good age and then suffered a series of strokes. Unable to look after herself, she left hospital to live in a nursing home. She was in a wheelchair, and unable to carry out what they call activities of daily living. She could pay for this as she sold her home.

After four years her life savings, including those from the sale of her house, were gone. Her health care needs were assessed at £70 a week. So she paid the rest herself, which came to £30,000 a year, and then, when her money ran out, she died.

Jane, her daughter, had power of attorney and managed her mother's affairs. Of course she had no inheritance now and for herself life was also becoming difficult. Still in her early fifties, she was diagnosed with early onset dementia: she had Alzheimer's Disease.

She had to take early retirement on grounds of ill health, with an NHS pension.

There was Disability Living Allowance to claim and a 25% rebate on her Council Tax. But the difficulty at first was not financial – it was getting the appropriate care. Services for a younger person with dementia were not easily found. No danger then of getting into an unhealthy dependency on the state.

For almost a year nothing much happened, as the adult services had no experience of working with dementia and Jane was too young for older people's services. The GP was the first to access social services – but only by getting the home from hospital team involved – a team with priority funding, because they were there to sort out delayed discharges from hospital – e.g., to save on NHS costs. Of course Jane was not actually discharged from hospital at the time but appreciated the sudden urgency that this introduced into meeting her needs. After months of inaction she had two social workers on her doorstep in 24 hours.

Slowly Jane and her family put together a mixed package of care. A local person who used to clean the house now came to be with her for companionship. The local authority stopped sending agency workers, who were always wanting to get on to the next job, because that was how they were paid, and Jane built up relationships with two or three trusted carers, who were paid for their time with her. In this way she could hold on to her appropriate autonomy and independence at home. But it was hard work for her and her family to negotiate all this with the local authority.

With her pension of £15,000 it was easy to make a financial assessment – she had to pay full whack. Each hour of local authority care would cost her £70 a week. For someone to come for one afternoon would cost £40. Her husband's small business suffered, as he put in more and more hours to manage her care, while the costs were rising to £400 a week.

Jane had the advantage of the medication that was only just becoming available for Alzheimer's. The drugs do not reverse or even slow the inevitable progression of the disease, but they made a big difference to her quality of life, as they alleviated the symptoms of confusion and disorientation. As the disease progressed, and she was now in the medium to severe stage, it became possible to think about combining donepezil (commonly but not universally prescribed in the NHS) with memantine. Except that it did not become possible. Despite clinical trials going back some years, NICE has yet to report on memantine, and on that basis Jane's PCT will not consider its use. The local psychiatrist was not prepared to discuss memantine, following the PCT directive. Jane might have early onset dementia but remembered well enough working in the NHS and she thought that a consultant's salary is a lot, if he is not then going to use his clinical judgement. It would be more efficient to employ a clerical assistant to make the decision. She went to a specialist who confirmed that it was appropriate for her to try the combined medication, but she still could not find a Trust prepared to meet the cost. The PCT assured her that it was in her best interest that they were not prepared to consider the only drug treatment currently available to alleviate the symptoms of advancing

dementia. So she found that she was paying for her medication as well as her social care out of her NHS pension.

This then was the reality of patient choice – not looking through brochures for different hospitals like planning a holiday. The NHS has saved on its drugs bill – after all the drugs do not make the patient better, but alleviate the need for social care – and the costs of social care, as we have seen, are not their problem.

But this expediency makes for very inefficient and more expensive provision of care. What in the end are the costs? For a professional person working in the public sector, earning an ordinary good salary, and then caught out badly by an unexpected and unpredictable life event, the financial costs are devastating. Imagine a professional couple – Jane and her husband for example – earning £80,000 or more in the final highly productive years of their working life - but then caught out badly by an unexpected and unpredictable life event. Their income collapses to £40,000 in one year, to £20,00 the next year, after four years they are drawing on capital to meet the costs of social care, which have risen from £5,000 to £10,000, to £20,000, and are set to double again, in the final stages of her illness. They still hope their children will inherit their house, if they are able to keep it - unlike her mother. Otherwise three generations in turn will have lost the financial security that they wanted for independent family lives.

Of course Jane still pays tax on her pension, and she is saving the NHS £1,000 a year by paying for her own medication, including VAT. And she is not yet a financial burden on the local authority – not until she is reduced altogether to poverty.

A state welfare system could be seen as a national social insurance to defend against such disasters – but is that good value for money for a government determined to encourage enterprise rather than support dependence? Nobody wants to know about vulnerability like that. And the real costs of the consequent unemployment, stress, and social isolation – as debilitating illness hits the economy of a whole family, not one individual - go unaudited.

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