

CARE OF THE VULNERABLE ELDERLY

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THE CRISIS OF CARE IN MODERN MEDICINE

That there is a crisis of care in modern medicine which impacts adversely on the vulnerable elderly is evident to many who use the NHS and who come into contact with it as relatives of patients.

Many official reports following investigations of failures of care in hospitals and related institutions confirm this. In July 2011 the Palliative Care Funding Review suggested how the delivery and funding of appropriate palliative care could be improved. Its remit arose from the *End of Life Care* Report of the National Audit Office in November 2008 which had noted three types of end of life care plan: 'The Liverpool Care Pathway', 'The Gold Standard Framework' and 'Preferred Priorities for Care'. But improving end of life care is only one of the challenges now confronting the health service and society in general.

In 2007 the British Geriatric Society admitted that the NHS was failing older people and not recognising the complex needs and dependency of the frail elderly.¹ In 2009, in its report *Equal Treatment, Help the Aged* noted the poll evidence that 66% of doctors specialising in the care and treatment of older people believed that older patients were less likely to have their symptoms properly investigated than younger patients. 72% of geriatricians said that older people were less likely to be referred for essential treatment. Julia Neuberger has written of 'a terrible attitude at the heart of the administration of the NHS that older people are worth less than the rest of us.'² More recently, Michael Mandelstam, an independent analyst who previously worked at the Department of Health, has provided a thoroughly researched study, *How We Treat the Sick: Neglect and Abuse in Our Health Services*.³ This extends his earlier research into 'systematic practices in the NHS' which revealed 'conduct causing harm, sometimes very serious, to vulnerable people.'⁴ He claims that such practices, common across the NHS, are an unintended, though not unpredictable, consequence of government policy, which has emphasised 'financial, performance and political targets' over 'humane care.' He notes that the report *Living well in later life*, published in 2006 by the Healthcare Commission, Audit Commission, and Commission for Social Care Inspection, recognised ageism, patronising and thoughtless treatment and lack of respect for the elderly by staff, as well as poor standards of care on general wards. The list of harmful practices identified included: serious neglect of infection and pain control measures; premature discharges from hospital; detrimental moving of patients from bed to bed and ward to ward; not helping patients with eating and drinking, or using the toilet; poor attention to hygiene; leaving some patients on a commode for hours, and failure to change soiled clothing and bedclothes promptly. In this way fundamental aspects of the health, welfare and human dignity of many individuals are being routinely undermined. Further examples of lack of respect for human dignity related to patients not being spoken to appropriately, failure to provide information or seek consent, patients being left exposed, inadequate attention to pressure sores, mixed sex accommodation, patients being left in pain and in a noisy environment without sleep, and patients being subject to abuse, violent behaviour, verbal threats and indifference.

Mandelstam claims that the obsession with targets, indicators and statistics, market forces and the use of business viability criteria for assessing success, inevitably marginalises the elderly whose health needs are usually complex and enduring and therefore difficult to meet. Put simply, from a

business perspective elderly patients tend not to deliver easy and clearly identifiable returns and this presents considerable challenges to prevailing attitudes in the health care system. Examples of strategies which disadvantage the elderly include the legislation in 2003 aimed at discharging especially elderly patients as quickly as possible from acute hospitals, the manipulation of the

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provision of 'NHS continuing care', and the contentious distinction between 'health care' and 'social care' which often creates funding battles between a local authority and the NHS, causing anguish to many. What Mandelstam calls the 'great rebranding' of health care into 'social care' achieves a reduction of workload for the NHS and transfers more complicated care to local authorities, with the added financial benefit that the latter can charge recipients for their 'social care'. Others too have suggested that this distinction promotes institutionalised injustice, variations in standards, and unequal charges for care, such as 'free healthcare for cancer and coronary patients but means-tested care for those suffering from Alzheimer's or Parkinson's'.⁵ In 1999 the Royal College of Nursing Report *Rationing by Stealth* stated that 30,000 elderly people had been wrongly placed in nursing homes when their medical conditions warranted free NHS care; typically, local authorities excluded from NHS care functions which were clearly nursing duties especially relevant to the elderly such as artificial feeding, pain control, terminal care, and catheter and stoma care.

In his most recent volume Mandelstam describes 'repeated patterns of neglect, scandal, indifference and half-hearted promises over a 14-year period.'(p.24) Surveying the ideals espoused in Government and Department of Health initiatives, policy statements and codes of conduct of medical and nursing bodies, and strategies of the Quality Care Commission and agencies concerned for the elderly, he amasses in almost 400 pages the considerable evidence of abuse, neglect, and failure to provide even the most basic care to many of the vulnerable elderly. This is a truly shocking indictment of the kind of treatment suffered by many older people in our hospitals. Since it is the elderly with multiple pathologies, among which some form of cognitive impairment is often present, it becomes clear that the most needy are receiving the poorest care. Mandelstam's main sources of evidence are reports from commissions, regulatory and investigative bodies and medical and nursing organisations, together with press and media reports, patient association submissions, the data bases of advocacy groups, coroners' findings and reports of official inquiries and court proceedings. He establishes that the deficiencies identified are not atypical, rare, or exaggerated, but systematic and endemic. He also rejects the view that since there is much good care we must simply overlook the failures.

THE GOVERNMENT VIEW

In 2001 the Department of Health Standing Nursing and Midwifery Advisory Committee observed that a 'large critical literature has been amassed which shows that current standards of care often fail to preserve older people's dignity, privacy, autonomy and independence.'(p.73)

Still, ten years later in February 2011 a report entitled *Care and compassion?* by the Health Service Ombudsman listed complaints about elderly care from many hundreds reaching the office annually. The dismissive attitude of staff to patients featured prominently. This was followed by instances of neglect: 'we read of tongues like dried leather, nutrition and hydration ignored, patients squealing with unmanaged pain, pressure sores thriving, call bells out of reach, lack of cleanliness and comfort, multiple unrecorded falls, the unavailability of bathing or showering, weeping wounds not dressed,



and an absence of patient monitoring.’(p.23) This list typifies the failures that Mandelstam recounts from every part of the country. Failing care ‘takes hold within individual hospitals affecting multiple aspects of basic care, and is found replicated in almost identical form across different hospitals.’(p.43) Many instances of neglect, bad practice and poor care are presented here, often in harrowing detail, and the nature and scale of the human suffering this involves is described in dozens of individual narratives. Since the official response of the NHS to complaints is often evasion and lack of cooperation it is important to attend to the sheer scale of the evidence accumulated.

Having noted the drastic reduction in beds available for patient care and the practice of leaving the dead on wards for long periods, Mandelstam deals in detail with the poor management of incontinence, the regularly reported leaving of patients in their own urine and faeces for lengthy periods and misuse of catheterisation (ch.7), in addition to poor cleanliness and infection control (ch.8), and failures to ensure help with eating and drinking (ch.9). In its response to *Hungry to be heard*, a 2006 report by Age Concern, the Government’s Nutrition Action Plan Delivery Board referred in 2009 to ‘widespread reports of malnutrition.’ Despite official expressions of shock and assurances of action, Age Concern renewed its complaint in 2010, and in 2011 the press reported that a hospital doctor even found it necessary to prescribe water for a patient! Inadequate prevention and treatment of falls, and failure to use proper pressure relieving equipment to avoid and treat impact sores and tissue damage, which cause so much pain and suffering, further reveal the extent of inadequate basic nursing care.(ch.10). Such lack of care and respect for the fragile bodies of the elderly in a culture so devoted to personal comfort and costly cosmetic pampering of the body seems especially repugnant. Chapter 11 records instances of the premature discharge of elderly patients, sometimes in the night without notifying relatives or carers. Chapter 12 completes this catalogue of poor care by noting how common are the reports of nurses detached, uninterested and often failing to speak to patients who then feel ignored and abandoned. Mandelstam describes an institutional indifference to the vulnerable elderly who have become effectively ‘the unwanted.’(p.171)

The main target of Mandelstam’s criticism is central government which is deemed ultimately responsible for the care offered by the state operated *National* Health Service. Central government bears direct responsibility for doubling management posts whilst radically reducing beds and nursing staff. That there are too few beds and too few properly trained staff, together with poor management, inadequate allocation of resources, a managerial ideology and structure that undermines clinical priorities and decision-making, and a prevailing mentality that fails to appreciate the basic needs of the vulnerable elderly, is a direct result of political and managerial decisions. The central thesis is that since neglect, abuse and failures of care are systematic, root and branch structural change is required. Though doubtless true, I believe that deeper questions must also be raised about the values of the wider society and about the nature of caring itself.

MY OWN OBSERVATIONS

Recently, I was able to observe for sixteen hours a day over three weeks hospital staff and their relations with patients, visitors, and colleagues on several different wards in an NHS general hospital. The workload of nurses and assistants caring for elderly persons with a range of needs was considerable. It was noticeable how the embedded culture of the hospital evidenced in attitudes, speech, and behaviour seemed a microcosm of society at large. That is not a surprising observation; we might say the same about many of society’s institutions and organisations. We all in so many ways, often unnoticed by ourselves, reflect the wider culture. The mass media is probably the major

conduit for the shaping influences of society on such institutions, and television soaps and similar fare supply models of behaviour, moral values, attitudes and forms of language and communication. It seems no coincidence that the ubiquitous television screen in many hospital wards and waiting areas provides not only a means of remaining in touch with this wider culture but a potential distraction from one's own immediate commitments. The number of times I noticed nurses and other staff watching or glancing at the television throughout the day when they were going about their duties was striking. Most patients seemed quite indifferent to the television, preferring more personal contact and communication or a little peace and quiet. This may seem a minor observation but I think such an intrusion hinders attentiveness to one another and a more natural communication by a word, a smile, a glance, or a gesture, which are the common currency of human relationships.

Other features of the wider society may also affect adversely the care we offer to the elderly, such as the pursuit of a very individualistic fulfilment, and the apparent difficulty of sustaining stable relationships characteristic of what is sometimes called the 'me generation'. The ridicule of the elderly by some popular comedians and negative portrayals of the elderly in the media are common. The financial exploitation of the elderly by unscrupulous tradespeople is well recorded. Government policies often fail to protect the elderly dependent. Increasing age can involve marginalisation or even abandonment by family and relatives. In addition, the elderly are increasingly defined as a 'social problem group'; in debates about demographic and economic pressures in the West the elderly are increasingly perceived as *the problem*. In passing, one may suspect that having systematically reduced the birth rate by a range of medicalised strategies, western societies will hardly balk at the task of implementing similarly hard-edged strategies to control the death rate. The social construction of elderly dependence and the idea of a generational conflict over resources seem to be distorting attitudes and behaviour towards this group, thus deforming the care we offer them.⁶ Mandelstam notes that in many complaints of patient neglect 'uncaring attitudes feature strongly' and reveal unsympathetic and negative attitudes towards old age, frailty and dependence on the part of some hospital staff. (p.229) The language of the market place with its 'customers', 'clients' and 'service-users' can itself damage the caring relationship. 'Bed-blocker' is now one of the milder demeaning types of bureaucratic shorthand, but still illustrates how certain forms of language can devalue the vulnerable.

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CARE IN HOMES

To examine the care offered in the independent sector is also instructive for understanding the 'crisis of care' in the NHS. Over several years. The National Care Standards Commission and Care Quality Commission identified numerous instances of failing care regarding the 'very basics of life.' (p.31) Broader evidence of poor care in residential and nursing homes reaches back to the 1970s. Since 'the history of British institutional care is littered with reports prompted by the discovery of mistreatment of elders', some even argued that 'institutional care was abusive in itself.'⁷ In studying how modern bureaucratic societies manage the death of their elderly Brogden noted that embracing the view that selfhood and personhood diminish with age and debility, a not

uncommon view in modern bioethics, effectively begins a process of consigning elderly persons to the liminal regions of society which 'makes them fit for disposal as detritus.'⁸ He speaks of 'bureaucratic disposal' in care homes as an 'impersonal termination process, with the full knowledge that a quarter will be eliminated in their first residential year.'(p.53) He describes covert rituals of stripping patients of individuality, regimentation of patients, ensuring conformity and compliance, assaults on privacy and other humiliations disguised by an apparently benign form of interaction between residents and staff whose attitudes are often depersonalising and infantilising. Many residents become 'an organisational unit to be managed as passive objects.'(p.119) A care home culture, with its routine management of death and disposal, may create an atmosphere in which neglect and abuse become easily tolerated, resulting in carers, who may already be ill-trained and poorly qualified, becoming numbed and desensitized and adopting 'varying degrees of detachment.'(p.185) Significantly, the failures of care associated with care homes have increasingly appeared in NHS institutions as the elderly who were originally rerouted to the former began to need the kind of acute treatment only available in hospitals.

CARE AT HOME

In addition to residential facilities care is also offered by local social services at home and it seems that neglect is not absent from these situations either. Again, under-investment, unrealistic workloads, shortage of staff and poor training are routinely identified as explanatory factors. But what of care offered at home by spouses and relatives? It is generally thought that such care reveals an extraordinary degree of motivation and many published personal accounts illustrate the commitment required, often for many years and involving far-reaching consequences for the carer's own life, career, health and well-being. Despite the presence of a deeper motivation rooted in pre-existing bonds of affection and devotion between elder and carer the level of stress can be immense.⁹ It has been said that often family carers 'will not place limits on solidarity such that their own wellbeing can be sustained.'¹⁰ The experience of isolation and the often constant struggle to secure the support of others, including GPs, social services, and healthcare services also contribute to carer stress. Since instances of mistreatment are not unknown in such circumstances perhaps we need also to acknowledge an even deeper and darker aspect to the 'crisis in care': one which connects us to our own moral fragility. Much care is difficult and demanding, emotionally and physically fatiguing, uncongenial and unpleasant. One's deepest desire to care competently, with love and compassion, can so often remain unfulfilled, leaving a sense of failure, frustration and inadequacy. Pope John Paul II suggested that part of the meaning of suffering was to 'unleash love', which is surely the response we would all hope for from carers.¹¹ But we often respond more hesitatingly and ambivalently to the suffering and vulnerability of others. It is a disturbing truth that the dependence on us of the vulnerable, perhaps especially the elderly infirm, poses a profound challenge to reach within ourselves for the resources to cope and to care, and in doing so we may find exposed our own moral inadequacy, emotional fragility and spiritual emptiness. Proper care will always require a solid support structure and careful apportioning of time for carer respite to avoid extreme stress and psychological depletion. To ignore the implications of this for the quality of care provided by professionals and non-professionals alike is to risk idealising the practical art of caring and to overlook the need for a serious moral and emotional education of those who care for the sick on our behalf.

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SYSTEMS FAILURE OR INDIVIDUAL MORAL RESPONSIBILITY

The emphasis on 'systems failure' commonly found in official responses to complaints about poor care tends to obscure individual moral responsibility; yet the moral character of individual carers remains a central question. There is something inherently morally challenging about every attempt to offer humane care in any context, and a discussion of a 'crisis of care' cannot avoid this issue. Though much basic patient care is now provided by health care assistants and similar carers, the 2007 Code of the Nurses and Midwifery Council (NMC) still emphasises the traditional components of nursing care, characterised by interested engagement within a personal human relationship. The NMC Code asserts that 'the people in your care must be able to trust you with their health and wellbeing' and then lists the requirements of the caring relationship, such as respect for personal dignity, friendly communication, attentiveness to the patient's needs, treating the patient kindly and considerately, and being an advocate on his or her behalf. The particular dependence and vulnerability of elderly patients requires even more from the carer in terms of patience and composure. Unfortunately, approaches to patients who may be confused or not fully aware of the nature of certain procedures relating to medication and monitoring often become perfunctory and insensitive. The limitations imposed by ageing, which commonly involve sensory impairment relating to sight and hearing, require the careful cultivation of a range of communication skills to provide the kind of comfort that settles worried minds and anxious hearts. Also essential are attitudes and behaviour that respect privacy and modesty. To create space for the elderly to express love, affection and gratitude is itself to respect their dignity. In such a relationship, a smile, a word, a glance, and a gentle touch can be powerful expressions of loving care. They do not exhaust the demands of care; but without them other aspects of care easily become unfeeling. It is a standard theme in medical education theory that there is a need to inculcate both humane benevolence towards the sick and suffering *and also* a certain emotional detachment to protect against psychological burnout. It is the former that seems in short supply in contemporary health care.

GOOD QUALITY CARE

Good quality care requires dedication and personal moral commitment to meet a range of needs in a manner that is considerate and humane. It has been said that 'because caring is concerned with the welfare of others, it is primarily a moral endeavour.'¹² It therefore requires a maturity that only a measure of life experience can ensure. Faith, spirituality and experience of informal care within family relationships are particularly valuable preparations for a professional career in caring. The need for care arising from dependence at certain times of life is a feature of being human and makes demands on members of the family, which is the first site of care that most of us experience. John Paul II envisaged 'a sort of "covenant" between generations' whereby care of the elderly is undertaken by those who were themselves cared for in childhood. (*Evangelium vitae*, 94) It has been said that 'to be cared for, to need caring, remains a permanent part of the human condition', but that modern medicine has 'managed to make caring seem like a second-rate activity.'¹³ The perception of caring work as menial and unrewarding, and the poor quality of training for many types of caring, contrasts with the 'new professionalisation' of nursing. However, Tallis adverts to a 'crisis in the nursing profession' illustrated by a proposal at the annual conference of the Royal College of Nursing in 2004 that 'nursing must decide whether educated well-qualified nurses should carry out only complex aspects of nursing and delegate the "touchy-feely" bits to others', such as health care assistants.¹⁴ Mandelstam thinks that more academically trained nurses will emerge but 'without the understanding and skills to undertake the profoundly humane activity of hands-on

care'. It can only be 'detrimental to patients – lonely, afraid, thirsty and left in pools of their own urine – for their nursing care to be separated from the nurses responsible for it.'(p.228)

Nursing textbooks continue to discuss the nature of caring in various health care settings, often exploring its moral dimensions and drawing on the work of theorists in care ethics. Some of these theorists reject the view that professional caring requires any moral commitment to the one cared for. But even if, as some research suggests, for most patients 'having friendly and helpful nurses is enough', this itself requires moral engagement.¹⁵ Others hold that caring is a virtue, involving a clear 'ethical orientation of the individual...an aspect of the internal life of an individual that is expressed in his or her behaviour.'¹⁶ We may suggest that whilst caring itself may not be a virtue it requires for its proper exercise certain virtues, central among which will be what St Thomas Aquinas called *miser cordia* (a term rooted in the idea of a 'compassionate heart'), a *mercy* that John Paul II called 'love's second name'.¹⁷ This is the form of charity that responds to, and seeks to alleviate, another's suffering, distress or affliction, through what we may call quite simply *loving care*.

CONCLUSION

Current codes and guidelines of professional nursing bodies show some awareness of a crisis of care and of the issues raised here. However, Mandelstam observes that the NMC, in its 2006 document *Registrant/client relationships and the prevention of abuse* fails to 'deal explicitly with the implications of collective perpetrations, or toleration, of neglect by nurses in health service settings.'(p.338) Since society asks nurses and other carers to respond to the individual needs of patients on our behalf we must all be concerned about how well they discharge this task. The vulnerable elderly deserve carers who are both competent and compassionate. By 2010 hospital admissions and stays for people over 75 had risen to 66%, and people over 60 accounted for over 50% of admissions in 2009-10. The NHS Confederation claims that the NHS spends 80% of its time and 80% of its resources on the elderly.¹⁸ Care of the elderly is thus becoming an ever more urgent issue that we must address if we wish to prevent suffering for countless vulnerable members of society. To tackle this problem requires a more realistic understanding of the demands on those caring for the dependent elderly, and attention to the cultivation of those qualities of mind and heart needed by carers. Above all, it requires a sustained commitment to the moral education of carers.

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