Editorial

PROBLEMS IN SEARCH OF SOLUTIONS

> Of all the wonders that I yet have heard,
> It seems to me most strange that men should fear;
> Seeing that death, a necessary end,
> Will come when it will come.
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> *Julius Caesar*, II.II.39–42

Depending on which particular calendar one has decided to follow, we have now either just embarked upon the new millennium or have just completed the first year of the new century. Whichever way the sands of time ebb away, it seems that as one gets older the merging of weeks into months accelerates at a faster pace. It is interesting to muse as to how the 'subtle thief of youth' is such a strange commodity: it can be lost, wisely spent, squandered, managed, accurately measured, but yet the profound understanding of the subtleties of this superficially familiar and elementary concept is fraught, even to those well versed in astro-physics and mathematics. What is certain, however, is that its inexorable progress cannot be defected, slowed down or accelerated.

Whatever the controversy about methods of time-counting and their accuracy, the advent of a new year is certainly a time for stocktaking, not least in the medical profession. The current era is increasingly becoming one in which the hinterland between ethics and medicine has never been more deeply fathomed and explored. A number of fundamental and sensational issues in this field have been explicitly highlighted by recent occurrences.

One such milestone which we have just passed is the presentation to the Lower House of a new bill (based on Dutch legislation) that in future would allow, and indeed decriminalise, the involvement of doctors in actively, materially and determinedly assisting their patients who request them to end their lives. To date, any actions Dutch medical practitioners admitted to taking to procure or assist mercy-killings have had to be reported fully to statutory regional medico-legal committees; after appropriate investigation and careful review by a forensic medical practitioner, in each case, these committees would exonerate the doctor if it could be shown to their satisfaction that the criteria laid out by case law in such matters had been adhered to. All this has now been put to one side.

The basis of acquiescence to such requests will depend on any patients' physician being entirely satisfied and indeed 'convinced' that they, 'in situation of hopeless and unbearable suffering', have made up their own mind, totally voluntarily and without undue and unreasonable coercion by relatives and friends or by financial pressures, to end their life, and that there is 'no reasonable alterative' for the 'unremitting and unbearable pain and suffering' that the patient is experiencing. Once all this has been established the doctor can prescribe and dispense a lethal concoction of drugs, and assist the patient with their administration. This change to the law dis-inculpates doctors completely when they perform such calculated and thought out acts. The bill has the full backing of the Royal Dutch Medical Association, and was championed by both the Minister of Health, Els Borst, and the Minister of Justice, Benk Korthals.

Some may consider that this is an old 'chestnut' to be left well alone, and anyway nothing has really changed in the Netherlands except for some regularisation and simplification of procedures. Be that as it may, it is certainly the case that the issue of euthanasia will continue to exercise the minds and emotions of the population at large and, at regular intervals, the attentions of the non-medical press and of politicians who may feel that their constituents are once again beckoning for resurrection of this issue. The medical profession has to retain this as an active issue for thought and debate.

It may be felt that such patients, experiencing despairing situations, require desperate measures. In sharp contrast, few can doubt that one of the more significant advances that has been made, to a major extent pioneered by Britain, is the hospice movement. A caring ambient is fostered in such establishments; those who are terminally ill feel wanted and cared for, and are even contented and at peace with the world at large, while residing in a non-judgmental, not necessarily religious, environment. In such caring communities, patients are individuals and their particular symptoms and anxieties are attended to specifically, palliated and, in the vast majority of instances, successfully relieved. Requesting a change in the law to bring euthanasia into the doctor's armamentarium, to my mind, slights and belittles the hospice movement and in this context renders it redundant, ill-understood and unappreciated. No matter that the condition may be terminal, and no matter the physical state of the patient, much can often be done by experts which is effective in removing pain and anxiety, and in salving the body, mind and spirit of these patients, and that of their families. To select the final exit option as a direct intervention is thereby also tainting the hands of those who have chosen and professed to be carers and healers with a non-beneficent, and indeed noxious, act. Any move in the direction of fostering euthanasia is empowering doctors in a manner that exceeds and flies in the face of their training and *raison d'etre*. Aggressive treatment of physical and mental pain and psychological hurt, no matter the secondary consequences, is the principle that should be publicised, and the minds of both patients and their distraught nearest and dearest thereby be put at ease.

The fall of the final curtain should not be allowed to occur prematurely and hastily, and there is scant and infrequent scope for this scene to brought irrevocably forward, no matter how dire the last scene of this 'mortal coil' is. Indeed, this was the reaction of a substantial number of members of the medical profession who were prominent among 400 or so signatures that appeared on 23 December 2000 in a newspaper advert. This was in public protest against the decision by Zurich city council to allow assisted suicides in institutions for the 'elderly and the infirm'.

Decisions about treatment at the end of life taken in advance of any critical illness, and any decisions taken regarding the institution, the withholding and withdrawal of aggressive and expensive life-support treatment of critically ill patients, are further ethical matters that exercise the minds of doctors with increasing regularity. On 21 December, the Catalan parliament had the support of all political parties when it approved a law legalising advance directives for terminal illness, provided that these are countersigned by three witnesses, of whom two are not related to the signatory. Others in Spain and elsewhere are likely to jump on the bandwagon.

When it comes to the withdrawal or non-institution of intensive care measures, the criteria on which such weighty decisions are taken have not been laid down specifically or categorised. Consultations with the families and the nursing and paramedical staff are a matter for the decision-takers at the time; however, there is a propensity to exercise a degree of medical paternalism which, although well-intentioned and often fully thought through in good faith, may not be in tune with the perceptions and aspirations of those other than the doctors who also have the patient's best interest at heart. The report of a prospective study carried out in 220 geographically widely distributed French Intensive Care Units[1] demonstrates the disparity that exists between different units, and the somewhat arbitrary reasoning that forms the basis for the conclusions reached at the end of these deliberations, even though passive euthanasia is outlawed by French law. Consensus guidelines have been published by well respected and authoritative American organisations,[2, 3] but other countries are yet to follow. Where does Britain stand?

Revelations that Harold Frederick Shipman, erstwhile General Medical Practitioner in Hyde, has been quietly disposing of many more elderly, and not so elderly, patients registered on his list than previously thought possible, have shaken everyone and have been met with renewed disbelief and hurt. Injections of diamorphine, apparently administered mostly during afternoon domiciliary visits, were the method of dispatch, with no apparent motive other than Shipman's experiencing a sense of power and megalomania. The now-public inquiry under the direction of Dame Janet Smith, a high court judge, is still to begin its deliberations and thus one can only speculate on its outcome. The absolutely fundamental assurance which the public require for the future is that the potential and possibility for such medically-mediated catastrophic and bizarre occurrences is abolished in no uncertain manner, and a closer watch is maintained to ensure that such diabolic occurrences are unlikely to recur.

The 'control' and accountability of so-called 'controlled drugs' in their movements from manufacturers, to the pharmacy, to the patient and beyond, must certainly fall within the ambit of what has to be done for the future. In spite of all the statutory regulations that are in place, and seem to be generally adhered to, it appears that opiates used pharmaceutically are too loosely dispensed and, once given to the patient, further accountability for them appears to dissipate into thin air. The euphemistic term 'leakage' has been coined by the drug agencies to describe this phenomenon, and this certainly has to be plugged further.

The main scope of this inquiry is an audit of death certification. Appropriate and accurate certification of causes of death, the opportune and timely discovery of concealed homicide prior to often irretrievable disposal of human remains, needs to be bolstered and tightened by appropriate legislation. An opportunity now presents itself to attempt to put matters right in no uncertain manner. To flaunt, squander and dissipate this opportunity would be unthinkable. This is unlikely unless there is a political will, transcending party dogmas and boundaries, to look carefully at the legislation that surrounds the various aspects of this case and amend them. To tinker around with regulations and guidelines, and leave the law as it stands, will be a whitewash and a travesty. Financial considerations are always important; not spending more than just the 'pennyworth of tar' that may be required at this stage in order to meet the defects that have been identified can leave the way open for yet another *cause célèbre*.

At the other extremity of life, a lasting poignant icon of this past year must certainly be the photograph of a young baby's hand holding tightly to that of her father. This picture has been replicated and syndicated worldwide into the public media, and has returned again in the end-of-the year published tally of images that were meant to characterise the year 2000. This photograph is of no ordinary baby but of the survivor of the conjoined Gozitan twin girls that were heroically operated on in Manchester, with the loss of the existence of one, and the re-fashioning of the body and the continued thriving of the other. The doctors caring for these babies, utilising the over-arching '*parens patriae*' jurisdiction of the civil courts, sought and obtained guidance from the judiciary who, cognisant of the burden that was being placed on them, felt obliged in this instance to speak publicly and to be interviewed by the press. Parental choice was set aside and over-ruled, and instinctive and religious-held opinions were tested, re-moulded, and changed in the light of principles enshrined in common law and in case law. The fundamental meaning of life and quality of life were dissected in the public arena. A blunder of nature has made many think and ponder, deliberate and argue, and consider fundamental life and death matters.

At the beginning of 2000 all were shocked and overwhelmed by pathologically graphic reports, on this occasion from the Old Bailey, that left little to the imagination and seemed hardly plausible, of the horrible and calculated homicide of an eight-year-old girl by physical and emotional neglect and protracted starvation. She had been sent by her parents to in-laws in this country in order to secure her a better future; instead, she was subjected to a nauseating, prolonged catalogue of abuse. Contact with the medical, social welfare and police agencies had been established, but signs which should have been blatant and obvious went unheeded and failed to alert the authorities.

Once again, as in similar historical juvenile cases of recent memory, co-ordination and co-operation between the individual services failed this child in a major way. In this context, the non-statutory associations that look after child welfare suggested that several children per week are still being horribly let down by their immediate families and by communities, and that the services that should be in place to monitor their wellbeing and keep them safe from physical abuse and neglect, although aware of problems, have not reacted to their plight. Occurrences such as this cannot be allowed to happen any more, and there can be no excuses for missing the blatant signs and for not acting in time. In their defence, it has been

indicated quite correctly that the agencies involved in child protection have to walk a precariously balanced tightrope between action and inaction. Confrontationally acrimonious encounters with families who are suspected of abuse may be retrospectively judged to be too heavy-handed and intrusive.

A closely-knit, seamless, transparently open, multi-agency approach that always involves the primary care and hospital carers and their teams, as well as child welfare and educational services, is required. Families have to be brought into the full confidence of the external caring team and to be made to feel that they are part of the decision-making process that involves their offspring, no matter what their background and their socio-economic ambient. Lip service has been paid with great regularity by all those involved to the tenet that the child's interests are paramount, and that all that is done in this sphere has to be child-centered as the child has no other independent advocate. Philosophical concepts have to be more actively and accountably put into practice.

Two other medical advances that occurred quite recently and which, to coin a phrase, will be certain to increasingly set the heather on fire, are the total unravelling and sequencing of the human genome, and the increasing scope of use of pluri-potential stem cells, harvested from embryos and bone marrow. Referred to as the 'full text of God's reference manual', the three billion biochemical letters that represent the chain of four bases that are strung together in the two strands of the DNA's double helix, spell out the words, phrases and sentences that make up the encyclopedia of existence. While each individual is a separate tome, similarities will be discovered in reading through the genomic texts of individuals with the same characteristics, and will enable identical characteristics and DNA sequences to be identifiable from spliced DNA retrieved from other individuals. The non-coding part of the DNA molecule has already been harnessed and put to excellent use in the forensic sector, to the extent that minuscule amounts of DNA, even if denatured by time and bacterial action, may still be sufficient to identify the perpetrator of a crime, provided that the laboratory processing, extraction, manipulation and amplification of the retrieved DNA is scrupulous in its detail. The day will dawn soon when debilitating and life-threatening diseases will be identified even before their manifestations have appeared; drugs will be manufactured that target specific receptor protein formation, that inhibit or augment their responses and interactions, and that attack disease at its pathogenetic source.

Stem cells can initiate and effect repair, and what were once thought to be 'permanent' cell populations can become reanimated and replete; specialised neuron colonies may become repopulated, and traumatically or chemically induced and degenerative neurological deficits may become salvageable by local implantation of such multi-talented primitive cells. Once again, the law had to be re-thought in the light of these latter medical advances. The Human Fertilisation and Embryology Act has been re-visited and amendments were made to it to enable research on early human embryos to proceed under careful scrutiny – at least in the House of Commons. This decision has once again tested deeply-held beliefs and concepts, and the arguments for and against justification of the means by the end have reverberated though parliamentary lobbies and family sitting rooms alike.

In the context of the latter advances, what many would wish to see is an evenly balanced contest between industry and academia. Pharmaceutical companies have not failed to notice that advances in molecular biology and human genetics may eventually reap extensive rewards in terms of diagnostic testing and design of new drugs. Academics working in universities with fewer resources and often inferior equipment may consider themselves at a disadvantage when compared to their colleagues in industry, where both equipment and personnel are more in concert with requirements. A concordat should be drafted for an enhanced partnership to be manifest between the two 'estates': academics need to retain and be guaranteed their autonomy, and yet they have to be allowed full access to the latest in equipment and sophisticated intelligence technology and computers, and also sufficient scientific personnel, and this can only occur through carefully crafted associations with the commercial sector.

Physicians, in their role as mentors and teachers, as indeed the epithet of 'doctor' denotes, must find time to distance themselves from the 'toil and trouble' of daily life and their direct caring of patients in all its varying guises. They must ponder and think deeply about matters such as the ones whch have been aired, and seek guiding principles which underpin decisions to be taken. The new visionary medical curriculum should also leave some time aside for the medical student and the young medic to be able to do just that. The non-thinking doctor is not a complete physician. In the style of Pirandello's play, a raft of fresh ethical questions are in search of answers, which have to be personally satisfying and conclusive.

As the Jubilee Year came to an end in the Vatican, and, at the end of December, the special door in St Peter's basilica shut closed, January 2001 – at least for some 70 million Hindu pilgrims – opened on an auspicious, happy and buoyant flurry of hope which has reverberated to all corners of the globe. In Allahabad, a promise of eternal salvation matched with a renaissance of spirit, and a shedding and cleaning of past misdeeds, awaits the visitors. In the Maha Kumbh Mela (the Grand Pitcher Festival) – an event that has gone on every twelfth year since 643 AD – ritual bathing in the confluence (Sangam) of the Ganges and Yamuna, with the mythical river Saraswati, guarantees this. Improvement in modern travel facilities has enabled so many more to take advantage of this gathering, this time round the event is even more propitious given the unusual configuration of the stellar constellations. The passage of time and the influence of the heavenly bodies yet again dictates and moulds human behaviour.

> For we, which now behold these present days,
> Have eyes to wonder, but lack tongues to praise.
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> *Sonnets*, C VI.13–4

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