Euthanasia and related ethical issues in dementias of later life with special reference to Alzheimer's disease

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Increased public interest and concern regarding euthanasia have been aroused in recent years by a number of developments. A succession of judgments pronounced by Courts of Law in different parts of the world have, in recent years, sanctioned the withdrawal of life sustaining procedures in cases of prolonged and irreversible unconsciousness and in patients suffering from painful and distressing terminal diseases. They have, therefore, pronounced euthanasia in these circumstances to be legally and ethically justified. This has generated wide ranging debate regarding the ethics of management of those judged beyond hope of recovery or improvement and near the terminal phase of their lives. The practice of euthanasia in The Netherlands, which has been in progress for a number of years, has also served to focus the attention of the medical and legal professions, and the public at large, upon the ethical, legal and clinical aspects of euthanasia. In the majority of patients, life had been terminated on request. But in a substantial minority, it had been undertaken on an involuntary basis. The scale of the practice of euthanasia in The Netherlands in recent years has yielded a vast body of information regarding the moral and practical dilemmas posed for doctors, families and society concerning patients who are chronically unconscious and ambiguously poised between life and death. As a high proportion of those whose lives were terminated were of advanced age, the lessons learned are closely relevant for the specific theme of this paper.

Euthanasia in The Netherlands

In 1993, the Dutch Parliament introduced legislation for the legal regulation of euthanasia. This had followed from analysis of the results of an investigation into life terminating actions in health care commissioned by the Attorney General of the Supreme Court. The findings of the enquiries and the effects of the new legislation have been reviewed in a recent ethical critique of the new law. Jochemsen reported that, of the 129,000 deaths from all causes in The Netherlands in 1990, euthanasia had been applied in 2,300 persons out of 9,000 who had
requested it. 400 persons had been assisted to commit suicide and, in 1,000, euthanasia had been applied without a specific request. In a further 22,500 persons, death had followed treatment for intensified pain or other symptoms either with the explicit purpose of shortening life or without taking into account the likelihood that this might prove to be a consequence of such treatment.

Some authorities have judged these developments as progress towards the humane practice of euthanasia. Jochemsen was critical and his conclusion, after a painstaking review, was that once official toleration or approval was given to the practice of life termination, it ‘develops a dynamic of its own that resists effective controls’. He judged the new legislation as protecting life no more and very probably less, effectively than did the old. It is evident from Jochemsen’s report that practice of euthanasia has escalated since the introduction of the new legislation. As the cause of death is stated in the death certificate as the original illness rather than euthanasia, the deliberate termination of the patient’s life is not declared. It is not, therefore, subject to legal supervision or review. The Minister of Justice has, however, recently announced that ‘as a general rule’ doctors reporting a case in which they have ended the life of a patient without his explicit request will have to face prosecution.

**Implications for Alzheimer’s disease**

These are challenging and disturbing facts. They are of particular concern for those psychiatrists and physicians who are engaged in the care of patients with Alzheimer’s disease and a number of other less common forms of dementia in late life. There are some 600,000 persons in the UK suffering from Alzheimer’s disease and approximately two-thirds of these patients spend the last 1–3 years of their lives or longer in chronic wards of psychiatric or general hospitals, or nursing and residential homes. They are in a progressively insensate state. It is one of the supreme ironies of this branch of medical practice that many patients with depressive illness in late life have compelling suicidal ideas and some carry them into effect. Yet, if the condition had been treated, the underlying depressive illness would have probably been brought under control along with the suicidal urges it had caused. ‘While there is depression there is hope.’ In contrast, those with advanced Alzheimer’s disease virtually never attempt suicide or ask to be put to death despite the intractable character of the disorder and the state of humiliating helplessness it causes. And there is no treatment that will cure or arrest the progress of this disease. Among those with advanced Alzheimer’s disease, it is relatively common practice to omit resuscitation when coma supervenes as the result of acute...
respiratory or other infection, stroke or cardiac failure. And, in some
cases with advanced dementia, treatment for some complicating disease is
withheld even though the patient remains conscious. But such practices
are inconsistent and rarely recorded accurately or at all. No criteria have
been set down to define, in a manner as precise and reliable as possible,
the clinical features of the declining ‘insensate’ phase of Alzheimer and
other forms of dementias. Nor have the moral and legal issues posed by
management been evaluated so as to ensure that such practices can be
kept within ethically acceptable limits.

The chronically unconscious condition, known as the ‘persistent
vegetative state (PVS)’ is irreversible in most cases after a duration of 6–
12 months. Alzheimer’s disease differs in two significant respects. During
the greater part of its course, no kind of vegetative state is present. A
vegetative state of a different character is manifest in the final 1–2 years
or a period of a few months. The Judgements pronounced regarding PVS
have provided valuable guidance for approaches to the ethical issues
posed by vegetative states. But their clarity owed something to the
relatively unambiguous and categorical nature of the issues in the case of
PVS. Secondly, whereas PVS is a condition of extreme rarity, Alzheimer’s
disease is a common condition in old age with a prevalence of 10%
among those aged 75 years and over and 20% among those aged 85
years and over. It represents a major medical, social, ethical and political
problem in the contemporary world. This cannot be said of PVS. Yet this
is the only disorder in which the many ambiguities and conflicting views
have been submitted to a searching analysis followed by authoritative
judgements in Courts of Law regarding the ethical and legal justification
of suspending life-supporting measures.

The clinical profile in the first few years of the mental deterioration in
Alzheimer’s disease differs in significant respects from the features of
PVS. But there is sufficient in common between the final insensate phase
of Alzheimer’s disease and PVS for the knowledge gained and the
judgements expressed about PVS to help resolve the current uncertainties
and moral enigmas posed by the more complex vegetative syndrome in
which the lives of those with the Alzheimer syndrome terminate. The
clinical features of the PVS and the judgements in the courts of the UK
regarding the therapeutic and ethical problems at present will, therefore,
be reviewed first in the sections that follow.

The persistent vegetative state

The syndrome was first described as a sequel of brain damage by Jennet
and Plum. Patients in a PVS appear to be awake, but exhibit no sign of
normal conscious awareness. Although their eyes are open, they respond neither to visual, auditory or tactile stimuli. They make vague sounds, but are incapable of speech or understanding, and cannot respond to communication. Respiration is unaffected, although artificial respiration may be required at intervals in some cases; eye movements are preserved, swallowing reflexes are intact and a sleep/wake cycle is maintained. They have, however, to be fed by a nasogastric tube, the bladder has to be evacuated by an indwelling catheter and the bowels by enema. Intermittent urinary infection is invariable and requires treatment with antibiotics. Although there is extensive destruction of the neocortex, the criteria for brain stem death are not satisfied. Moreover, to his relatives, the patient appears alive with his eyes open and in some movement. His breathing appears most of the time to be spontaneous and effortless, but help with artificial ventilation may be intermittently required. They are incapable of voluntary movement and can feel no pain. Although seemingly awake with eyes open, they do not perceive their surroundings and, like comatose patients, they make no response to stimuli. Those with PVS do not suffer only from the total loss of their cognitive functions. Their ability to feel or express emotions is destroyed; they neither smile nor shed tears nor show signs of anger or hostility. The presence of residual emotional faculties would have enabled them to emit some primitive signals or communications to others. There is no recognisable vestige of their erstwhile features of personality manifest. The patients appear alive, awake, breathing normally, and a brief involuntary movement may be interpreted as a response to a question. Hence, relatives initially find it difficult to understand the seriousness of their condition.

There is evidence from postmortem studies that patients with PVS in whom the condition has persisted for months or years have suffered extensive damage to the cerebral neocortex. The brain stem is, however, intact and vegetative reflexes such as breathing, swallowing and cough and gagging reflexes are maintained.

After 3 months of unconsciousness in PVSs not caused by trauma, recovery, usually with severe residual disablement occurred only in 7% of cases. After 6 months in a PVS there were no recoveries. The Medical Ethics Committee of the British Medical Association has stressed the imperative need for early medical treatment and nursing care, courses of intensive stimulation and the provision of appropriate nutrition, as offering the best hope of the partial recovery that may follow in a proportion, usually with residual cognitive deficit.

It will be evident that the cerebral functional systems, that had mediated their cognitive skills, emotional responsiveness and their individual traits of personality, cannot have been totally destroyed from the outset in all cases. For, in the first few months, they can be re-activated with the aid of an intensive programme of stimulation, feeding
and repeated arousal. This course of events ensued in the celebrated case of an 86-year-old lady, Carrie Coons. It was subsequently argued that she may not have been a typical case. But this is not strictly relevant.

Some other chronic syndromes of chronic helplessness

In the course of a number of the hearings, passing reference was made to other rare conditions that pose problems similar, in certain respects, to those of the PVS. They include the ‘locked in’ syndrome due to a haemorrhage in the pontine part of the brain stem, which deprives patients of all voluntary motor control except for movements of the eyelids and vertical gaze. But they do not suffer from unconsciousness or cognitive failure. They are awake and vigilant, though able to communicate only through their eye movements; there is total paralysis of their other muscles. Such patients present fundamentally different and particularly difficult ethical problems in that they are able, albeit with difficulty, to express their wishes about their fate. Their basic personality must, therefore, be relatively intact. Another rare phenomenon mentioned was an advanced case of Guillain-Barré syndrome in which there was total paralysis, but no mental impairment. Yet termination of life had been sanctioned on the strength of the request made by the patient, who was unable to endure his totally helpless state. It would have to be established, as far as possible, that such a person was not passing through a transient state of despair through depression before acceding to such a request.

Judgement regarding therapeutic, ethical and legal aspects of PVS

On 9 December 1992, the Court of Appeal in England considered an appeal against a judgment that had been made in the Family Division of the High Court in the case of Anthony Bland, who had sustained crush injuries of his lungs in the Hillsborough Stadium disaster. As a result, he suffered cerebral anoxaemia which caused irreversible damage to the cerebral cortex of his brain and left him in a PVS from which he had shown no sign of arousal over a period of three and a half years. It was ruled in the High Court, in a judgment delivered by the President, Sir Stephen Brown, that it was permissible for the medical staff in charge of the patient Anthony Bland to discontinue procedures that had been required to preserve his life. In these terms Sir Stephen was granting the declaration sought by the Health Authority responsible for the hospital where the patient was receiving treatment.
The case was referred to the Court of Appeal (Bingham, Butler-Sloss and Hoffman) which ruled that the medical staff caring for the patient would be judged as acting within the law if they discontinued life sustaining measures from Anthony Bland. Artificial hydration and nutrition were assumed in this judgment as constituting medical treatment. There had been unanimity among the medical authorities regarding the diagnosis of PVS and in respect of the opinion that there was no hope of recovery or of improvement in his condition. Treatment would have been of no benefit to the patient and the principle of the sanctity of life was not, therefore, violated by its cessation. On the other hand, the invasive manipulation of his body involved in life support actions, for a patient who had been in PVS for more than 3 years, was not to be regarded as a duty; doctors were not entitled to continue it, since the patient could not have any further interest in the prolongation of what was a mere existence rather than a life in any real sense. The intrusive measures employed constituted a violation of his dignity and the integrity of a human being and his right to a peaceful death.

The decision of the Court of Appeal was upheld in the House of Lords to which it had been referred in a final appeal. The contributions made by the Judges in the Court and the House of Lords constitute one of the most comprehensive evaluations of the ethical, philosophical and legal aspects of those who have been permanently deprived of their higher mental faculties and are in a chronic and intractable state of unconsciousness. It is worth quoting one passage from a judgment in the Appeal Court hearings in full, in that it set out, with particular clarity, the main principles that require consideration when decisions are being formed regarding the justifiability of suspending life sustaining treatment in chronic states of unconsciousness. The statement of Lord Justice Hoffman was in close accordance with that made by the other Judges in the Court. Its particular relevance in the present context resides in its intellectual and moral authority and the clarity with which he discriminated between forms of management of those trapped in a state of incurable mental oblivion, which are ethically and legally valid, and those which are invalid, because they violate the principle of sanctity of human life.

In my view, the choice which the law makes must reassure people that the courts do have full respect for life, but that they do not pursue the principle to the point at which it has become almost empty of any real content and when it involves the sacrifice of other important values such as human dignity and freedom of choice. I think that such reassurances can be provided by a decision, properly explained, to allow Anthony Bland to die. It does not involve, as counsel for the
Official Solicitor suggested, a decision that he may die because the court thinks that his ‘life is not worth living’. There is no question of his life being worth living or not worth living because the stark reality is that Anthony Bland is not living a life at all. None of the things that one says about the way people live their lives – well or ill, with courage or fortitude, happily or sadly – have any meaning in relation to him. This in my view represents a difference in kind from the case of the conscious but severely handicapped person. It is absurd to conjure up the spectre of eugenics as a reason against the decision in this case.

Thus in principle I think it would be right to allow Anthony Bland to die. Is this answer affected by the proposed manner of his death? Some might say that as he is going to die, it does not matter how. Why wait for him to expire for lack of food or be carried off by an untreated infection? Would it not be more humane simply to give him a lethal injection? No one in this case is suggesting that Anthony Bland should be given a lethal injection. But there is concern about ceasing to supply food as against, for example, ceasing to treat an infection with antibiotics. Is there any real distinction? In order to come to terms with our intuitive feelings about whether there is a distinction, I must start by considering why most of us would be appalled if he was given a lethal injection. It is, I think, connected with our view that the sanctity of life entails its inviolability by an outsider. Subject to exceptions like self-defence, human life is inviolate even if the person in question has consented to its violation. That is why although suicide is not a crime, assisting someone to commit suicide is. It follows that, even if we think Anthony Bland would have consented, we would not be entitled to end his life by a lethal injection.

On the other hand, we recognise that, one way or another, life must come to an end. We do not impose on outsiders an unqualified duty to do everything possible to prolong life as long as possible. I think that the principle of inviolability explains why, although we accept that in certain cases it is right to allow a person to die (and the debate so far has been over whether this is such a case) we hold without qualification that no one may introduce an external agency with the intention of causing death. I do not think that the distinction turns upon whether what is done is an act or omission. The distinction is between an act or omission which allows an existing cause to operate and the introduction of an external agency of death.

To evaluate the relevance of the judgements pronounced regarding PVS for the most highly prevalent form of dementia, namely Alzheimer’s disease, requires a preliminary review of the diagnosis, course and the features of the form of vegetative state in which the disease terminates in most patients.
The clinical features, course and complications of Alzheimer's disease

Diagnosis of Alzheimer's disease

The first and foremost clinical and ethical duty of the psychiatrist or physician is to exclude the possibility that he is dealing with manifestations of normal ageing or with some relatively benign and treatable condition rather than the illness most dreaded by elderly persons.

Many of those in the seventh or later decades of life begin to experience some impairment of memory. The deficits that accompany normal senescence are mild, inconsistent, circumscribed and non-disabling. The skills required for negotiating the tasks of everyday life are largely intact, emotional life is preserved and deterioration does not follow.

Depressive illness with the slowing of thought and movement and the loss of self-esteem and confidence it engenders has to be considered and the increased risk of suicide, in men in particular, born in mind. Appropriate treatment abolishes or relieves the symptoms in most cases.

A wide range of metabolic and other physical diseases may mimic primary dementias, such as Alzheimer's disease. Tumours of the frontal or temporal lobes, chronic subdural haematoma, myxoedema and vitamin B\textsubscript{12} deficiency can cause progressive mental deterioration with cognitive impairment as the main feature, although emotional characteristics and the personality are better preserved in the secondary dementias than in Alzheimer's disease. Sub-acute bacterial endocarditis has, in recent years, become more often manifest in old age and middle life. Dementia may develop as a non-metastatic complication of bronchial or other carcinoma but the primary condition sometimes remains occult. A dementia-like illness may develop in association with the 'atypical hyperthyroidism' of elderly persons and during long courses of treatment with steroids. A high standard of clinical vigilance and care is essential, since the symptoms of many forms of physical illness are relatively 'silent' in the aged with fewer conspicuous symptoms than in the young. Yet only in those diagnosed and treated at an early stage is there hope of reversing or arresting the progress of mental deterioration.

Stages in the progression of Alzheimer's disease

During the greater part of the course of Alzheimer's disease, which may endure for 7–8 years and more in some cases, there is no sign of coma or of a PVS unless some complications, such as a stroke (in 'mixed' cases), a
head injury following a fall, or a severe infection (such as pneumonia or septicaemia), supervenes as an additional complication. Otherwise, comatose or PVSs occur only in the final 1–2 years or few months.

In the first stage of about 2 years, symptoms comprise impairment of memory, decline of interest and a gradual diminution of capacity for reasoning, calculation and abstract thought.

In the second stage of 3–4 years, progressive intellectual impairment, personality deterioration and lability of the emotions, followed by blunting and apathy, occur. Focal psychological deficits combine to present more clear evidence of an advancing degeneration of the cerebral cortex. Impairment of language is reflected by increasing difficulty in naming objects and finding words. During the later parts of this stage, there is increased loosening in the cohesion of language and difficulty in the expression and comprehension of speech. Growing impoverishment and impediment in writing and reading reflect progressive demolition of the regions in the brain concerned with storage, integration, and creative use of language. Apraxia renders the patient dependent on others for dressing and bathing and he becomes incapable of feeding himself or responding to requests or commands. Agnosia adds to confusion and incompetence in daily living. Mood disturbance, usually a depressive disorder associated with retardation or agitation, may become manifest at this stage in many patients in this phase of the illness or earlier.

A proportion of those affected are aware of the decline in their mental faculties and, fearing a mindless state, ask for their lives to be brought to an end. There is rarely, if ever, any medical or ethical justification for responding to such requests and deliberate termination of life is unjustified and illegal. The self-destructive ideas emanate in many such patients from a depressive disorder and the symptoms usually respond to treatment drugs and psychotherapy, often with some improvement in cognitive deficits.

Towards the end of this phase, there are disturbances of posture and gait, an increase in muscle tone and, in about 25% of patients, a delusional hallucinatory psychosis with a fluctuating course makes its appearance. Delusions are mainly concerned with dispossession, displacement and persecution and generally respond to treatment with neuroleptic drugs.

A sudden steep decline of consciousness with mental confusion, incoherence of speech, unresponsiveness and sudden onset of incontinence may be due to acute clouding of consciousness or delirium. This always has a specific physical cause, such as pneumonia, gastrointestinal infection with dehydration, or transient cerebral ischaemia. Many such complications respond to treatment and the symptoms of ischaemic episodes usually resolve without residual disablement. The individual remains recognisable as the person he was in a substantial proportion of
patients and some retain a limited and variable ability for verbal and emotional communication with others.

But, in the early and middle stages of the disease, the ethical, medical and psychological problems posed for those responsible for the care of the patients are more, paradoxical and difficult to resolve than they proved in the PVS. A limited range of intellectual functions remains. There may be disorientation, memory is severely impaired and speech incoherent. But for brief spells at a time, the patient shows signs of comprehension and recognition of the identity of husband or children and friends is manifest. Facial expression breaks through the mask of apathy and unfolds towards a smile and then the eyes fill with tears. Something of life with features characteristic of the manner in which the person lived remain. In a frail, enfeebled state and, as judged by the rate of progress of the dementia, only 2 or 3 years of life remain. But, for some relatives, the continued life of a loved mother or father or spouse in this state is deemed precious. Death is for them an enemy to be defeated until all individual traces of personality and mental life have been expunged. Their feelings have to be treated with respect and consideration.

No categorical imperatives can resolve such issues and decisions have to be taken on an individual basis. Psychiatrists and physicians have an intuitive repugnance against permitting a treatable respiratory infection or other complication to terminate the life in an aged individual whose emotional responses are relatively well preserved, who seems able to communicate and exhibits a measure of autonomy. Such intuitive reactions have to be heeded, subjective as they are, for they stem from a reverence for the sanctity of life. Once a doctor begins to silence and ignore these signals, he will have become susceptible to other influences. He may begin to allow his judgements about treatment to be shaped by pressures that stem from scant resources, pressures on space and the distress or inconvenience of relatives. All these deserve a place in his total appraisal but it is the plight of his patient which must be accorded the greatest weight and be placed at the focus of his concern. Once he wilts under other influences, he may be prevailed upon at earlier and earlier stages of the illness to wonder whether treatment of Alzheimer’s disease, or other dementias, is necessary or desirable. The clinician’s desire to heal or relieve illness and suffering and the edge of compassion may be imperceptibly blunted step by step by arguments of expediency.

In the advanced stages of the disease during the last 1–2 years (though in some patients longer), the condition of patients with Alzheimer’s disease has many features in common with that presented by patients with PVS. They are bereft of speech or other means of communication. They have neither memory of the past, retention of recent events nor evidence of any intellectual activity. Emotions, whether of pleasure, melancholy, irritation, anger, distress or affection, have all been
obliterated. Only a profound and unvarying apathy prevails. A high proportion of patients are bedridden, immobile, doubly incontinent, unable to recognise their relatives or friends or their own reflection in the mirror. They require help with feeding, dressing and they are totally oblivious of their humiliating, totally helpless, condition. This state can be described as vegetative. Owing to weakened gag and swallowing reflexes, part of the food and drink administered passes down the respiratory tract into the lungs. Before the end there may be a period of ravenous appetite accompanied by an incongruous and progressive emaciation.

Neurological signs, including spastic paralysis or a near-Parkinsonian form of rigidity and in a small proportion grand mal fits, make their appearance. Progressive enfeeblement is manifest. When complete and sustained unconsciousness develops at such an advanced stage, in the absence of a definable recent complication, coma soon follows and signals the beginning of the end. The only form of humane and ethical management in the event of an attack of pneumonia or lapse into a coma is expressed in the exhortation 'vex not his ghost'. Attempts to resuscitate such patients restore patients to an existence that is not a life in a real sense. The process of dying should in patients with Alzheimer’s disease who have reached this stage be allowed to proceed to the end.

Advance directives or living wills

Living wills enable people to provide advance directives regarding what will happen to them in the event of irreversible disease or provide authority to one person to act on his/her behalf should they become incapable of making decisions regarding the manner in which they will be treated as their lives draw to a close. Living wills began in the course of the ‘Right to Die Movement’ in the US in the 1960s and were embodied in California’s Natural Death Act in 1976. Since that time, 37 states in the USA have enacted ‘right to die’ legislation.

Some advance directives can be judged as authentic, competent and informed after the patient’s clinical state has been taken into account and his probable state of mind at the time when the document was drafted has been investigated with relatives or others. In cases of Alzheimer’s disease and other dementias, considerations have to be weighed in others deciding on the action to be taken in the event of an acute complication such as the development of a respiratory or gastrointestinal infection, or a descent into coma. The appropriate course may be to allow the patient
to die in peace. But pain, restlessness or agitation have to be brought under control with drugs.

However, having regard to the host of problems that have arisen following ‘living will’ legislation in the USA, it is open to question whether the instructions embodied in such wills should have been accorded compulsory force by law. As the wills are also permitted to specify life prolonging procedures to extend life, physicians are obliged to provide such treatment to the maximum extent possible. The action requested may conflict with the doctor’s clinical judgement and ethical standards. The humiliation caused to patients, who may retain some residual awareness of the insensitive procedures entailed in life prolongation, and the distress caused to relatives are also ignored in many living wills. And scant heed is paid to the increasing burden created for the limited resources available. The clinicians’ freedom to act in accordance with the condition and the needs of each individual case is undermined.

The freedom and independence with which he can decide and act is also precluded by law. He is unable, in cases of mental deterioration, to consider the circumstances in which the living will was set down and the possible relevance of the course of the illness in the period that has intervened. The directive might, for example, have been formulated soon after the patient’s condition was diagnosed as incurable. He may have suffered at the time from a depressive state and been under the influence of nihilistic hopelessness, guilt and suicidal ruminations. In the years or months that followed, his condition might have changed. He may, or may not, have been offered an opportunity to revise his advance directive.

Some individuals, as for example those who suffer from longstanding morbid fears of being buried alive when they are only deeply asleep or suffering from an illness that renders them unresponsive, may prepare a bizarre living will requesting that after death has been diagnosed, they be kept under medical observation for some weeks or months. Permission is accorded for his burial at this stage, that is if no signs of life have been elicited during the stipulated period.

There may be compelling reasons on the grounds of the clinical state of the patient and compassionate concern for the ordeal to which he and his family were being exposed for overriding a directive. Heintz\(^\text{12}\) has given a disturbing account of the lengthy and acrimonious legal controversies and struggles that have been generated in every state of the USA by ‘right to die’ legislation. He points out that poorly drawn wills ‘could lead to erosion of patient’s rights rather than fulfilment of patients’ choice’. He concedes that legislation is required but that ‘greater care must be taken to avoid the creation of a Kafkaesque legal nightmare for those we intend to assist’.
Dilemmas in clinical practice common to PVS and Alzheimer’s disease and differences between them

For purposes of the comparison to be undertaken in this section, a brief summary of the Judgements pronounced by the Court of Appeal and the House of Lords and the Address by Lord Justice Hoffman should prove helpful. It was made clear and given special emphasis by Lord Justice Hoffman that doctors are morally precluded from taking life with intent. There is no legal sanction for such behaviour even in patients in terminal stages of their illness. A second point lays stress on the qualitative difference between killing and allowing the process of dying to continue without interference. This point deserves some comment from the author. Doctors who offend against this principle will be liable to damage the quality of the personal relationships they can establish with their patients. From being perceived as healers they will also come to be regarded as executioners. For if the physician approaches even demented patients with intent to end life, he is in danger of clouding and confusing his moral judgment. It has been suggested that the fundamental humane sensibilities firmly ingrained in the personality of doctors are modified once they begin to engage in killing. We should have learned from the history of the past century, and the Nazi era in particular, that once they begin to engage in killing, the practice is liable to become habitual and undertaken with progressively weakening stirrings of conscience even in some previously respectable, socially upright persons including doctors.

A third point affirmed that individuals who are completely unconscious and oblivious to persons and the whole world around and capable of neither pain nor pleasure are insensate and have no life to live. They, therefore, need to be protected from further erosion of their dignity and integrity by being allowed to die. Fourthly it was asserted that, in such situations, cessation of medical treatment and artificial feeding should be judged as being neither illegal nor unethical.

The first two principles summarised above are unequivocally relevant for the final vegetative stage of Alzheimer’s disease. But in respect of the third, and to some extent the fourth, principle there are significant differences between the two conditions. Alzheimer’s disease is the most highly prevalent and far-ranging destroyer of the quality of human life in old age and, if these last two principles were to be uncritically applied to Alzheimer’s disease during the greater part of its course, harm could be done on a vast scale.

To quote from Lord Justice Hoffman’s statement ‘the stark reality is that Anthony Bland is not living a life at all’. This statement was apposite for a patient who had been unconscious owing to PVS for more than 3 years. But it is applicable only to the last chapter of Alzheimer and other
forms of dementia which may, of course, drag on for 2–3 painful years and in some cases longer. In the early and middle stages, there may be considerable cognitive impairment, but in her demeanour and emotional interactions she will often be clearly recognisable as the person she was and may need only limited help in dressing and bathing herself.

This point needs to be developed further in the light of one view widely advanced in recent years, that once the personality of a human being has been irreversibly erased he should be judged as suffering from 'brain death'. This is equated by some to death of the person and is implicitly regarded as providing grounds for withholding medication in the case of infection and other illness and avoidance of resuscitation from coma due to some treatable disorder. It was subsequently stated that such steps would be appropriate only for patients in lasting coma. But what criteria are to be employed for determining 'death of personal identity' in the sense used above? The patient with Alzheimer's disease of 3 or 4 years' duration may be incoherent of speech and lacking in understanding and may at times fail to identify her relatives and be intermittently incontinent. During periods of delirium due to acute infection, she may be totally inaccessible. But she usually recovers consciousness if treated. And some are able to smile, express gratitude for a visit with a few words or a surge of pleasure and warmth in the expression of the face which dissolves into a trickle of tears.

Her personality has not irrevocably lost all liveliness, interest and the gift of concern for and involvement with others. From the point of view of integrity of the personality, such patients with Alzheimer's disease are more intact than those with advanced chronic schizophrenia, who exhibit total apathy, inertia, utter incoherent sentences to themselves and emit incongruous giggles or laughter while they sit in isolation from others. No one has suggested for the present that chronic schizophrenics should be allowed to die if they fall physically ill or be submitted to euthanasia. We have no precise or reliable means of establishing end points in personality and self-awareness. There is no one region or specific functional system in the brain where the personality can be located and no investigation with brain imaging or other objective neurobiological assessment that provides a measure of the extent to which personality has been eroded.

It may be that once a firm diagnosis of Alzheimer's disease has been established and the faculty for intelligible communication and understanding have deteriorated, patients with this disease will come to be, and perhaps already are, among those whose lives are involuntarily terminated. If so, medicine and society may have unwittingly wandered onto a slippery slope. It may have moved to a position close to adopting similar practices in patients with Downs syndrome with or without dementia and other forms of mental handicap.
In a proportion of those with Alzheimer’s disease, who may appear on routine examination to be totally blank, there may be latent faculties and skills that can be activated to bring to light the survival of distinctive personality features and at times rare and special gifts. This can be illustrated by describing a patient who was aged 80 when first seen. She had been deteriorating for 3 years but remained emotionally responsive and attractive in appearance. Speech was incoherent and memory, orientation and intellect were severely impaired. She was occasionally incontinent of urine. She had been a pianist of distinction since her teens and she continued, despite dementia, to perform the works of classical composers with delicacy and initially with an impeccable technique. The interpretations were all her own, the play of emotion transfigured her facial expression and one had a strong impression that her music played a part in the conservation of her general emotional responsiveness. Four years before she died, she went into coma during an attack of pneumonia. She could have been allowed to die but she was treated and recovered. She continued to play for a further 18 months but with declining skill. She remained, until about a year before death, an affectionate and responsive human being but devoid of cognitive faculties in the last 2 years.

Most patients who suffer from Alzheimer’s disease during the last few years are, however, in a kind of vegetative state in which none of their erstwhile personality traits are in evidence. They are bedridden or restricted in mobility, helpless and inaccessible. The only humane course at this stage is to cease medical treatment and to desist from resuscitation from coma or clouded consciousness due to acute infection, cardiac failure or other illness. The crisis in the health services arises to an extent from growing demands that are being made by the rising proportions of elderly who are succumbing to Alzheimer’s and other forms of dementia and with disabilities which make large and steeply escalating demands on scant resources. An increasing proportion spend their last years and die in institutions. Some of the apathy, retardation, inattention and even some of the cognitive impairment in the middle phase of the disease arise from the destruction of morale and general stultification generated by the institutional environment. Subsidies to families to enable them to care for their deteriorating relatives to survive for longer periods in their own homes—and to die at home as they used to do until recent decades—might improve the plight of a proportion of those with Alzheimer’s disease in their final years. The prevalence of vegetative states among those cared for in a domiciliary setting as compared with those in long term institutions poses a question worthy of investigation.

There is also need for wider emulation of the example set by Cicely Saunders and her followers in the hospice movement in respect of the sense and sensibility with which they care for those in the later stages of progressive mental deterioration, including Alzheimer’s disease.
The principles enunciated in the Court of Appeal and the House of Lords provide valuable guidelines for appraisal of the ethical aspects and for the management of the rare disorders with chronic unconsciousness such as PVS. They also shed light on some of the ethical and clinical problems posed by the different kind of vegetative syndrome, manifest during the last few years of Alzheimer's disease. Although some philosophers tend to be sceptical of the distinction between killing and letting die, most doctors must retain the distinction between the two. Their attitude is informed by a moral sensitivity deeply ingrained by ancient traditions and by training and experience, which compels them to 'pause' so often in the course of decision making.

In relation to Alzheimer's disease, the intensity of this moral imperative survives despite all the pressures that impinge on doctors towards its suppression. Doctors are often urged at the present time to 'hasten the process of dying'. To accept this as a general principle would be contrary to ethical sensibility. In the case quoted above, the patient could have been allowed to die of her pneumonia. Letting die could have been defended in the present climate of opinion in a case of well advanced dementia. But her personality was perceived as dignified and inviolable. She continued to evoke affection and transmit it to those close to her. It was judged that to desist from treatment was to give premature sanction to a 'letting die' policy in the management of this patient.

However, in other cases of the same disease, treatment would restore patients to a travesty of life. These cases approximate to the vegetative state which forms the basis of the judgment regarding Anthony Bland in 1992.

For these and other already discussed reasons, the judgments summarised earlier have a more limited application than in the case of PVS for the clinical and ethical problems that have to be resolved during the 3–6 year early and middle stages of the course of Alzheimer's syndrome. For in this disorder, speech, memory, understanding, judgment, independence and personality undergo gradual, rather than suffering instant, obliteration.

There are 600,000 patients affected in the UK and their number is expanding. They constitute a growing medical, social, political and ethical problem of immense dimensions. Neither medicine nor society can remain entirely indifferent to the arguments that flow from scant resources. For this would deny the justice of the claims of children and the young who have to wait for months or years to receive treatment in hospital. But more thought and energy will have to be invested before an equitable and balanced reconciliation of every relevant dimension of the dilemmas that confront medicine and law as also patients, families and society can be achieved.
There is a faint flicker of light in the dark tunnel in which society finds itself. It stems from the rapid advance made by scientific research in the past 10–15 years towards defining the causes of Alzheimer's disease. There is at least some promise that methods of arresting the progress or the disease, and possibly preventing it, may emerge.

References

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11 House of Lords Judgment. Airedale NHS Trust vs Bland (J L (E)) pp 835–99