

## Commentary

# 'Round-table' ethical debate: is a suicide note an authoritative 'living will'?

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## Abstract

Living wills are often considered by physicians who are faced with a dying patient. Although popular with the general public, they remain problems of authenticity and authority. It is difficult for the examining physician to know whether the patient understood the terms of the advance directive when they signed it, and whether they still consider it authoritative at the time that it is produced. Also, there is little consensus on what spectrum of instruments constitutes a binding advance directive in real life. Does a 'suicide note' constitute an authentic and authoritative 'living will'? Our panel of authorities considers this problem in a round-table discussion.

**Keywords:** advance directives, autonomy, critical care, living wills, medical ethics, suicide

## The scenario

Harry was found near a smoking gun with his face severed from his skull. He was still breathing, so paramedics inserted an endotracheal tube and took him to the emergency room, where he displayed strong vital signs and ventilated well, with normal oxygen saturation. Surgical evaluation revealed that he had succeeded in removing everything from his chin to his ears and to his eyebrows, and had exposed and damaged numerous cranial nerves. In addition, no normal anatomical landmarks could be discerned. Debridement and a permanent tracheostomy were performed, and the remaining skin folded over.

By way of past history; Harry never got much of a break in his 46 years of life. Unsuccessful marriages, failed jobs, and severe depression resulted in multiple psychiatrists and multiple suicide attempts. On this occasion, emer-

gency teams were called to investigate a gunshot reported by his neighbours.

As the anaesthesia wore off, recovery room staff were horrified to see Harry raise his left hand and examine his facial packing. An immediate neurological examination showed that he used his left arm in a semi-purposeful manner, but was otherwise unresponsive – he had deep tendon reflexes all around, and did not withdraw from painful stimuli.

An electroencephalograph demonstrated 'diffuse slowing', but no other acute abnormality. Auditory evoked stimuli showed no hearing function, and coded commands on Harry's palms and chest did not result in a response in the good arm. Occasionally, Harry raised his left arm briefly into the void, but he was otherwise unresponsive.

Harry's suicide note read "I have decided that life is too painful for me to continue trying. I want my family to know that I have thought about this and I believe it is the only way out. Please forgive me and go forth with your own lives." His only son was contacted, but he declined to make any decision on his father's behalf because they had been estranged for some time.

On final assessment, Harry could not hear, talk, smell, see, or move anything other than his left arm. Over a period of days, Harry developed an aspiration pneumonia requiring multiple antibiotics, constant suctioning, and pulmonary toilet. He would require permanent tracheostomy, feeding tube and skilled nursing home care should he survive.

## Should Harry's suicide note be interpreted as a living will?

### What actually happened

#### David Crippen

What would a reasonable person think if they took steps to effectively end their life, and then 'woke up' with no sensory ability at all, except searing, diffuse pain in quiet darkness? Of course, they would think they were in Hell.

Most living will laws allow patients to die of an untreatable disease process if they have written evidence that they would not want to be sustained with life-supporting technology [1]. Harry left a convincing living will. He stated clearly and lucidly his desire to be relieved of his life, and the only reason that he is more or less around for us to worry about is because he bungled the suicide attempt. Because Harry has no ability to care for or protect himself, without continuous, intense and invasive medical care he will surely go on to die.

Thus, Harry's disease process is eventually terminal, he is in constant pain and he has a *de facto* living will that clearly states his wishes [2]. He meets all of the criteria that any ethics committee would readily agree to. However, some physicians still think Harry might want to take a chance on life again, with no ability to participate in any of it.

Expert consultants say that we are obligated to artificially prolong Harry's suffering because he cannot tell us his current wishes [3]. This assumption must be made because Harry was impaired as a result of depression, a potentially reversible disease. Impaired people cannot be discriminated against, and so must be covered by substituted judgement. The possibility exists that Harry's sobering experience has jolted him to a realization that life may be worth living after all, and we must give him the benefit of that doubt. His seemingly authentic living will must not be viewed as authoritative.

The attending physicians feel Harry should have all life support removed and be allowed to die because his suicide note demonstrated clear evidence of his wishes – a variation on a 'living will'. The psychiatrist disagrees, however, stating that "The desire to commit suicide is necessarily pathological and treatable. In the past, Harry has changed his mind and called paramedics after ritual suicide attempts. He cannot have been competent to make the decision to die. We cannot give authority to it, and we cannot know his current wishes. He must be maintained as if he had changed his mind and decided to live. That he is now disabled doesn't enter into it – disabled people routinely choose life and treatment."

I find it interesting that these consultants have lost the concept of what rational humans would do if faced with unimaginable horrors. Has anyone in this group ever observed a sane person to proffer a living will stating their premorbid desire to be placed in a nursing home on a ventilator, feeding tube and dialysis? Then maintain that existence with frequent trips to emergency departments and ICUs to maintain vital signs and laboratory values, and to repeat the cycle over and over, until they finally die of some process that cannot be temporarily reversed?

As a practical matter, I think Harry is in need of someone to take charge of the situation, eschew vacuous ivory tower academic diatribe and simply do the right thing [4]. Therefore, as Harry's physician, and acting in what I feel the clinical evidence suggests in his best interest, I have gathered all the nurses and staff to Harry's bedside to say the following:

"You all know Harry here. Harry decided that he did not want to participate in life anymore. He wrote these wishes in a note that I believe is authentic and authoritative. Harry then tried to end his life in a very effective manner. No 'call for help' gestures. Harry meant it. Unfortunately, Harry also botched it, and now his situation is infinitely worse than when he started on this course.

It has been suggested by consultants that Harry might have changed his mind and desires us to continue his suffering, and cannot tell us his wishes. As a practical matter, I do not believe that this is the case. If Harry's psychic pain made him miserable in life, he now has sensory deprivation and physical pain/discomfort superimposed. It is inconceivable to me that Harry would want to live in this terrible world we have created for him.

Therefore, as Harry's physician, I have decided that what we're going to do is take his 'extraordinary' artificial life support away and compress five million years of natural selection into the next thirty minutes. If Harry survives off the vent and all other modalities except 'ordinary care' – nutrition, hydration, a clear airway and comfort measures – then we will give our consultants the benefit of the doubt. Harry will get a percutaneous enteral gastrostomy feeding tube and transfer to a nursing home. However, if Harry cannot survive with the 'ordinary' care that everyone deserves, then Harry will die as was his premorbid wish."

Requiem – the reverend asked me if I wanted to say a few words at the graveside:

"I did not know Harry before I met him under the most difficult of circumstances. I was placed in a position of having to deal with a lot of things about Harry that I don't understand, like depression and suicide. I asked a number of my colleagues to help me best deal with Harry's dilemma and received a multiplicity of thoughtful answers. These well-meaning consultants almost uniformly followed society's hard lines in dealing with society's anomalies. If a person assumes a philosophically uncomfortable attitude, we must always err on the side of assuming that they would snap back into political correctness if given another chance. I was Harry's doctor. I felt Harry's pain and I ended it because, in the end, the preponderance of evidence as to Harry's wishes pointed in a direction that seemed authoritative and reasonable. The decision ultimately came down to me and I made it. In my heart of hearts I think it was the right thing to do. If it wasn't – God help me."

### **We cannot acquiesce to emotional convenience** **Donald B Chalfin and Cory Franklin**

Advance directives, or living wills, are inherently complex, and often ethically and emotionally challenging. Even under the best of circumstances, in which an informed and thoughtful individual who is fully cognizant of all options and sequelae, drafts and executes a comprehensive document and appraises others of his or her wishes, almost all advance directives contain flaws and uncertainties. It is nearly impossible for even the most informed and introspective person to anticipate all events and possibilities. It is even more elusive to address issues of certainty regarding the wishes of unfortunate patients who failed to or were unable to convey their decisions, and establish competency, cognition and even consciousness to allow these wishes to be executed.

This case depicts a complex scenario with many confounding and almost unfathomable variables and consequences. From a clinical standpoint, one cannot argue with the notion that this is a most unfortunate and gut-wrenching situation; Harry's failed suicide attempt led to horrific clinical consequences of overwhelming and permanent disability, profound disfigurement, and complete and utter dependency on others and society in general for all aspects of his care. Instead of ending his life and alleviating his 'pain' as detailed in his suicide note, an opposite – almost unimaginable – course of action occurred. Even in the best-case scenario, all that Harry's clinicians can hope for is a 'stabilization' of his status, with the eventual placement of a tracheostomy and feeding tube with life-long care and residence in a nursing home. Meaningful cognition and basic human interaction will be lost forever.

From the perspective of clinical compassion, one can fully sympathize with and admire the desires of the attending physicians to alleviate the patient's suffering and attempt to honour his 'wishes'. However, the suicide note cannot be considered a living will, and thus life support should not be removed at this point. From the standpoint of the individual patient who has specified or desires to draft and stipulate an advance directive, competency is essential. In the majority of suicide cases, depression is a major component and contributing factor, and therefore it has the real potential to alter competency and comprehension of the vital issues. This case is further confounded by the fact that the patient's injury led to the permanent inability to evaluate whether depression was present when the act occurred, and, if present, whether it influenced the patient's underlying competency and ability to comprehend the meaning of his acts and wishes. In essence, the psychiatrist is correct in his statement regarding the presence of pathology – depressive or otherwise – and the current status of the patient prevents one from ruling depression and related pathologies in or out. Thus, one must assume, barring the presence of new information, that the potential for depression did exist when the patient attempted to take his life, and therefore that this obviates the assumption that the suicide note might be considered, in whole or even in part, to be a living will.

In addition to the concerns that are specific for this and any other individual, one must reckon with the fact that society (or the state) may override patient autonomy and obviate one's wishes, even if those wishes were expressed by a conscious and competent individual, should four potential conditions exist that warrant contravention: (1) the prevention of suicide; (2) protection of a third party; (3) maintenance of the integrity of the medical profession; and (4) the preservation of life. In this case, it can be argued that up to three of these conditions exist (1, 3 and 4) and therefore that, even with the tenuous assumption that competency was present, discontinuation of life support must not ensue under the present circumstances.

Clearly, then, it is incumbent on the physicians and all care givers to look further and delve deeper into the issues, in order to have the required medical and ethical diligence to establish prior wishes and directives. In the absence of this action, and/or assuming that new information may not exist or cannot be uncovered once all investigative measures have been exhausted, the attending physicians should continue to treat the patient and provide comfort measures, in addition to therapeutic support and maintenance of his vital functions dictated by medical necessity. Although this case is emotionally searing and one that tests the will and compassion of all involved, we need to remain ever cognizant regarding the potential ramifications of all of our interventions and actions, and their associated nonactions and noninterventions (ie the proverbial 'slippery slope'), which may extend beyond this particular case. In short, as much as we may cringe about the ghastly state of affairs, we cannot acquiesce to our passivity or 'emotional convenience' and let patients die because they may have unresolved issues – clinical, psychiatric, or otherwise – that result from our failure to act on their behalf in advance in their time of need, and to do our utmost to expeditiously address these underlying needs and unanswered questions. Only when we exhaust all of the investigative options on Harry's behalf to truly discern his pre-existing desires, wishes and state of mind will we be able to consider a different course of action.

### **Depression, like cancer, can be refractory to treatment** **Jack K Kilcullen**

The easy answer as to why a suicide note should not substitute for a living will is that any will, whether intended to take effect before or after death, serves as an instrument of human action, enforceable by the courts, when the actor is not capable of being heard. Safeguards are therefore essential, and for that reason a document that is intended to carry out a person's desire to die should possess the same evidence of freedom and capacity as a document intended to dispose of bank accounts and furniture. Special language, multiple signatures and witnesses are not mere formalities; they provide evidence that must serve as the legal equivalent of a person's live declaration.

The more difficult question concerns Harry's right to die. The living will and the suicide note represent the light and the dark side, respectively, of the profound cultural ambivalence that exists in the USA between a belief in the sanctity of life, and the right to live life as freely as the constraints of a civilized society would permit. On the one hand, the USA is a deeply religious nation, certainly by European standards, with much higher rates of religious observance, in which politicians infuse their electoral themes with overt professions of belief in God. On the other hand, there is an abiding disdain for secular authority in the USA, where even the national constitution is

couched in terms of limitations on government power. Life as a gift from God is considered sacred, yet we give people remarkable freedom to waste their lives. Debate over abortion and the death penalty reflect this tension between authority and freedom at its most extreme; many believe that the right to life is sacred before birth, but can readily be squandered when someone commits a capital crime. Consequently, in the hospital setting, we obey a sense that life is sacred and will not substitute our judgement for God's, even when it means leaving a person to languish for years in a failing body, suffering the inadequacies of our custodial care. Only individuals themselves can choose to forego that care through some judicially recognizable declaration, and allow their bodies to fail as they believe God might have intended all along.

Like the living will, the suicide note states a desire to have an end to life when only suffering and despair seem likely to fill the months or years left. Americans treat this in a different manner historically, because however much we believe an individual is free to sin against God, we consider suicide itself a sin and will not be a party to any of its implications. Moreover, modern psychiatry, with its ability to manipulate the levels of key neurotransmitters, has given suicidal ideation rooted in depression a pathophysiological basis for treatment. However, the fact that thousands escape the best tools that psychiatry possesses and take their own lives tells us that, for some, depression is incurable. This was Harry's situation at the moment he pulled the trigger. For all his previous gestures, hope had finally run out. Both his words and his deed give compelling testimony to the pain Harry suffered, and to his desire to finally bring it to an end.

So now we stand at the bedside of a terminally ill patient who is without a living will, but has provided ample evidence of his wishes. Even the Court of Appeals in the State of New York would find 'clear and convincing evidence' of Harry's desire to terminate the medical support necessary to maintain his life. We do not really need to distinguish between the means of support, be they artificially derived respiration (the ventilator), artificially derived immune resistance (antibiotics) or artificially derived nutrition (tube feedings). It is clear from the totality of the evidence, and not just the suicide note, that Harry would have had none of it.

The question of Harry's competency to make the decision to die cannot simply be assumed away as the psychiatrists would, as if the suffering of depression is somehow bearable, while that of chronic pain is not. Although it is a tenet of psychiatry that 'the desire to commit suicide is necessarily pathological and treatable', Harry's depression, like many cancers, was refractory to treatment. Moreover, any living will expresses the broader belief of society that the desire to die, rather than being a mental pathology, could be the most courageous expression of sanity a person

may ever make. Through the living will, we allow people to define the terms for withholding treatment by which we will assist them in committing suicide as assuredly as if we had handed them a gun.

So, let Harry die with all the best palliative care we can offer. Our best compassion as healers comes when we match the grace of our patients with our own humility.

### **Advance directives: expressed wishes or mandatory guidelines?**

**Stephen Streat**

The scenario as portrayed does not ring true in a cultural sense in New Zealand, and I suspect in a number of other countries with similar ex-British legal and medical traditions and institutions. I first discuss the relevant areas of legal, medical and cultural difference, and then describe what would probably happen in this country if such a patient were to arrive at the emergency department.

The concept of the living will, or advance directive, is well known to New Zealand intensivists, but the reality is that these documents have had little impact thus far on clinical practice.

First, we have read several advance directives that have been given to us by the families of American tourists who have become critically ill while visiting our country. My personal experience is notable in that, without exception, these individuals have indicated either the wish to avoid prolonged intensive care support of multiple organ failure or have requested the withdrawal of intensive therapies in the event of severe damage to the central nervous system. Both of these practices are common, without living wills, in New Zealand intensive care units.

Second, the concept is now explicitly described in New Zealand legal documents. Section 11 of the New Zealand Bill Of Rights Act of 1990 [5] states that "Everyone has the right to refuse to undergo any medical treatment." More recently, The Code of Health and Disability Services Consumers' Rights became law on 1 July 1996 as a regulation under the Health and Disability Commissioner Act of 1994 [6]. This code mandates that "Every consumer may use an advance directive in accordance with the common law."

Third, in response to the enabling legislation and regulation, the New Zealand Medical Association [7] has produced a guide for patients on advance directives [8]. Included in this is a discussion of the circumstance in which a 'health care provider' doubts the validity or applicability of a 'consumer's' advance directive. Crucial to this discussion are four points: whether the consumer was competent to make the particular decision, when the decision was made; whether the con-

sumer made the decision free from undue influence; whether the consumer was sufficiently informed to make the decision; and whether the consumer intended his or her directive or choice to apply to the present circumstances. The guide goes on to suggest that "If the doctor believes that complying with the advance directive would be contrary to the consumer's best interests, then the doctor needs to consider consulting another person or authority that is legally entitled to consent or refuse treatment on the consumer's behalf, for example, parents, legal guardians, welfare guardians, and the courts."

Fourth, there have not yet been any circumstances in which such advance directives have been challenged through the courts. It is currently unclear to what extent and under what specific circumstances the documents might be binding on intensivists looking after legally incompetent patients. In particular, our concerns as clinicians have centred around the difficulty of trying to encapsulate, in a generic document, the specific circumstances in which patients may find themselves in the future. It commonly seems, in our reading of advance directives written in other countries, that they do not fit the actual clinical circumstances with sufficient precision to enable an unambiguous interpretation of the writer's prior intent. This concern is often echoed by intensivists in such countries, and has recently been discussed [9] by a psychiatrist from Australia, a country that shares cultural and legal traditions and has very similar intensive care practices to those of New Zealand.

Finally, we have not yet encountered such a document in our Department of Critical Care Medicine during the 4 years since the enabling regulation came into effect. I believe that when and if such a document does appear, we will treat it as a generic statement of previously expressed wishes, but not necessarily as a mandatory and binding document.

As a personal aside, it seems ironic to me that the apparent motivation for the advance directives we have read has been fear of prolonged suffering. How sad it is that we should be viewed as potentially responsible for this suffering by practicing our profession in a way that is driven either by technological imperatives or by a fear of litigation should intensive therapies be withheld or withdrawn. What place does our profession hold in society when such documents are required to ensure that we practice with compassion and common sense? If this is the near future of intensive care medicine, then I and many other New Zealand intensivists will be questioning our motivation to practice our wonderful craft.

Turning now to the case in question, it seems clear to me that the suicide note cannot be viewed as a living will within the guidelines for such documents in New Zealand. However, we would not feel the need to have a living will

before withholding or withdrawing intensive therapies in a patient in whom these actions seemed the correct course to take.

Our approach to this patient would probably have included intubation, ventilation and immediate surgical debridement. This would have been followed not by early tracheostomy, but by an early, meticulous and serial sedative-free clinical central nervous system assessment, supplemented by neurophysiology and imaging studies. Usually this would involve computed tomography and somatosensory evoked potentials, and occasionally other studies including electroencephalography, brain-stem auditory evoked potentials, visual-evoked potentials and magnetic resonance imaging. Should this assessment, which may take a few days, confirm that severe brain damage has occurred, then we would seek to withdraw intensive therapies in the context of a formally documented consensus process, involving first the intensivists, then any other involved clinicians, and finally the family.

This process, which is in accord with a recent European viewpoint [10], has been well established in our department for many years, and is robust and flexible. We have previously illustrated the process with clinical examples [11], and more recently reported on the apparently satisfactory bereavement outcomes for the surviving next-of-kin that occur in a department in which such a process is common [12].

In practice, in the scenario as presented, it is likely that such a process would have occurred before the onset of nosocomial pneumonia, and that antibiotics would not have been given when that complication occurred. A psychiatrist would certainly not have been consulted and the suicide note would not have been considered as possessing the potentially legal legitimacy of a living will.

### **A suicide note is not a living will**

**Robert D Truog**

Unfortunately, as the concept of a living will has increasingly permeated both medical culture and lay society, its meaning and purpose have been distorted. This case is an excellent example of how inaccurate understandings and muddled thinking can lead to unnecessary confusion.

A living will is one form of advance directive. A typical living will is a document that describes certain clinical conditions that may occur in a patient after they have lost the ability to make decisions for themselves, such as advanced Alzheimer's disease, or dependence on mechanical ventilation in an intensive care unit. The document then allows the patient to indicate preferences for the type of care that he or she would like to receive, if they were ever faced with being in a similar condition. Of

course, in reality the situations are never identical to those described in the hypothetical scenarios, and so acting in accordance with a patient's living will must always involve some degree of interpretation.

This is where the other form of advance directive, a durable power of attorney for health care, becomes so important. In this document, the patient indicates the individual that they would like to have make health care decisions on his or her behalf, in the event that the patient should lose decision-making capacity. Therefore, the durable power of attorney for health care specifies exactly who has responsibility for interpreting the living will. Ideally, then, the two types of advance directive work together toward the goal of treating patients in the way that they would want to be treated, should they ever be in the position of not being able to make decisions for themselves.

In the light of this, it should be obvious why it is inappropriate to interpret a suicide note as a living will. First of all, a living will can only be executed at a time when a patient is rational and competent to make his or her own decisions. Anyone holding a loaded gun to their face need not apply for membership to this group.

This alone is sufficient to invalidate the linkage between a suicide note and a living will. There are additional problems, however. If we take the suicide note seriously as a guide to how this patient should be treated, then the patient's clinical condition should be irrelevant. Imagine, for example, that the patient blew off his leg instead of his face, and was bleeding to death. Suppose he never lost consciousness, and upon arrival in the emergency department refused treatment, waving his suicide note in the air and telling everyone that he wanted to die. I would be surprised if many clinicians would agree to withhold treatment under these circumstances.

The real question we need to answer here is simply "What is the best thing for Harry under the present circumstances?" Hasty judgements, such as "We should let him die because he wanted to commit suicide," or "We must keep him alive because he is now disabled, and most disabled people want to live" only serve to trivialize the complexity of the question. We need to take everything into account: the horrible reality of his current condition, and the psychological and social realities of his life – severe depression, a profound sense of failure and an estranged family.

Even standard legal and bioethical jargon such as 'substituted judgement' and 'best interests' are too simplistic to answer the question. Substituted judgement tries to answer the question in terms of what Harry would want for himself, if he were able to decide. The fact that Harry is suicidal, however, makes the situation more complicated. Just as we would not allow an otherwise healthy individual

to leap from a tall building if we could stop them, so we should not let Harry die just because he is suicidal. The 'best interests' standard is inadequate also, however, because it assumes that we can make a judgement about what is best for Harry in the absence of considering the totality of what it means to be Harry, including the fact that he is in a deep state of despair.

I do not know the correct answer to this case, but I do know that it cannot be solved by equating a suicide note with a living will, or by assuming that all disabled people want to live. From the description given, I think my initial judgement would be to adopt a palliative approach toward Harry's treatment, with the goal of making him comfortable and with the expectation that he would not survive. However, this is a choice that could only be made by those at his bedside.

### **Defining 'extraordinary' care is key** **Leslie M Whetstone**

Equating a suicide note with a living will is ethically dangerous, and is likely to lead the public into unhealthy perceptions as to the role of physicians in society. By any current ethical standard, it is best to keep suicide notes distinct. That is not to say, however, that Harry's note should be disregarded and that he should necessarily be maintained in this hopeless state of existence.

I will argue that, even though a living will is not present, life support systems may be considered extraordinary care and hence ethically forgone. Therefore, Harry may be allowed to die a civilized death.

Whether or not we believe in rational suicide, or if anyone agrees with Harry's actions, we need to address the current reality. Arguing over Harry's competency, and attempting to determine whether his decision was 'autonomous' makes little practical sense at this point in the progression of events. The damage has been done, and we are charged with bringing about the most humane outcome possible. The consultants who believe Harry was depressed and irrational may well be right, but is this still an issue? Do we make him live because he wanted to die? Not only is that counterintuitive, it is barbaric and ethically indefensible at this point in time. We are not in a position to judge Harry or his motivations, but to promulgate the best possible decision from a series of bad ones.

In the absence of a surrogate decision-maker, and without any knowledge of what Harry would have wanted, it is generally considered appropriate to utilize a 'best interests' standard, a paternalistic approach that tries to determine what a reasonable person would want in this particular situation. However, in Harry's case we

have a detailed past history. We know that he was troubled, that he attempted to end his own life on numerous occasions, and that psychiatric interventions always failed. In this regard, one may wonder whether we can use the 'substituted judgement' standard. That is, act according to how we know Harry himself would have acted; in short, let him die specifically because he wanted to die. This is contrary to the expert consultant above, and ethically speaking we need to examine it more closely.

Working from what a reasonable person would want, it seems that Harry's current existence would be unacceptable. However, quality of life is a dangerous thing to judge, because different people may have different opinions on what is acceptable. Therefore, it may be more meaningful to draw from Harry's past. We know that he was dissatisfied, and, incompetent or not, those feelings of dissatisfaction were authentic for him. For instance, no matter how irrational it may be that I fear spiders, it stands that if I truly fear them, then for me that fear is my reality, and no amount of rationalization may ameliorate that fear. The same holds true for Harry and his desire to die, for even though his death wish might have been irrational, he could not be helped by psychiatry, and to him it was his reality that he would be happier dead than alive. Whether or not we recognize the pathology is irrelevant at this point. Thus, to compel treatment now, when he was miserable before this predicament, is unconscionable.

Furthermore, when we assess the treatment modalities required to maintain Harry, we need to consider all of the effects that they produce. What are the holistic benefits of the ventilator? I would argue that the burden of being suspended in this existence via the ventilator far surpasses any benefit to Harry. He cannot interact, and he cannot recover; thus, to impose life support on him to extend this suffering is misguided.

I also take issue with Dr Crippen's 'Darwinian Tolerance Test', which would involve removing what he describes as 'extraordinary' support and letting nature take its course. I have two different objections to this proposal.

First, Dr Crippen conflates the terms 'ordinary' and 'extraordinary' treatment. Working from Catholic medical ethics, ordinary versus extraordinary treatment is a moral distinction, not a medical one [13]. That is, a treatment is no more extraordinary than any other because it happens to be high tech. A course of antibiotics can be regarded as extraordinary treatment, whereas a ventilator may be regarded as ordinary; it simply depends on the person and the situation. In this tradition, morally extraordinary treatment may be forgone, but morally ordinary treatment may not, as we have a responsibility to respect life, but not to prolong it at all costs [14].

When considering what is specifically extraordinary or ordinary, a variety of factors that are pertinent to the individual must be considered. For instance, what are the burdens and benefits of the treatment? What is the degree of discomfort the procedure may cause? What is the emotional consequence of the treatment, and what is the cost? However, Dr Crippen erroneously concludes that, because nutrition is relatively easy to give, it should be considered ordinary, and therefore compulsory. Such is not uniformly the case, as nutrition and hydration can be regarded as medical treatments, and forgone just as any other medical treatments.

We have to ask why Dr Crippen will withdraw a vent and let Harry die, but insists on introducing a feeding tube that will artificially prolong his life. This is simply a substitution of one intervention for another; the result of maintaining either modality defeats the purpose of relieving Harry's suffering. The provision of nutrition and hydration is not palliative, because it is maintaining Harry's existence, which we agree is too painful to be endured. Furthermore, the notion that percutaneous enteral gastric tubes are palliative by nature has been disputed, as they can cause oedema, aspiration and a host of infections. To withdraw a vent but start enteral feeding is inconsistent.

My second concern regarding Dr Crippen's analysis is his readiness to relinquish Harry to those consultants he appears to argue against originally. Should Harry survive extubation, Dr Crippen maintains "we will give the consultants the benefit of the doubt", and thereby transfer Harry to a nursing facility. This dubious statement negates his prior position that "I think Harry is in need of someone to ... do the right thing." What is the right thing? To see whether he can breathe on his own and, if he does, to hand his care over to those who want to maintain him indefinitely? It does not matter who is given the benefit of the doubt, so long as the patient's interests are served; therefore, what the consultants want should be of little concern, if their wishes are contrary to what we perceive is the right decision here.

In conclusion, although I agree with Dr Crippen's desire to do the right thing, his argument falls short because what he says he wants to do is not what he ends up doing. If we use an argument of best interests standard, coupled with considering Harry's past life experiences, whether or not we agree with them, we can get a sense of what will be the best course of action for him. In addition, invoking the beneficence principle of doing well for patients and withholding treatments that impose more burdens than benefits, it is ethical in this case to withdraw life support. Life support in this case will also include artificial nutrition and hydration, as these are not palliative measures, but cause a prolongation of suffering.

## Conclusion

David F Kelly

Despite the bizarre nature of the case, it and the comments of the discussants raise important substantive and procedural issues. The main substantive question is what ought be done. As is usual, the procedural question is who ought to do it and how. Both have ethical and legal implications. In the case itself, the attending physicians want (probably) to do the right thing for the wrong reason, and the psychiatrist would do the wrong thing for both right and wrong reasons.

### The value of the suicide note

The attending physicians, and David Crippen, want to consider the suicide note an advance treatment directive. This is legally perilous and ethically wrongheaded, as other discussants have pointed out. Robert Truog's alternative case (in which the injury is less severe) is compelling. Competent patients have the legal right to refuse treatment, and there is some serious disagreement among scholars about how to determine competency and about how much competency is needed to make definitive decisions in varying circumstances. However, few would accept as definitive even the contemporaneous refusal by a suicidal patient of treatment that would, more or less quickly and easily, restore him or her to health. To do so is to misunderstand autonomy and what it requires. Suicidal tendencies are properly seen as reducing decision-making capacity. In this the psychiatrist is correct.

However, it is true, as Leslie Whetstine points out, that the note ought not be automatically disregarded. There is no legal requirement that I am aware of to ignore written requests that persons have made simply because the documents lack certain formal characteristics (signatures, witnessing, special language) required by state laws. As Jack Kilcullen notes, these characteristics do serve to provide supporting evidence of the writer's intentions, but many state laws on advance directives are, either explicitly or implicitly, 'cumulative legislation'. They do not restrict rights people had before they were passed. Thus, people can still write down or talk about their wishes in other less formal ways, and this evidence should be considered.

The discussants disagree about the evidence, if any, that the note provides. Crippen states that it should be seen as a *de facto* living will. Kilcullen agrees with most of the round-table that it cannot be that, but wants nonetheless to give it serious weight. He appears to think that withholding treatment is the same as assisted suicide: "... we will assist them in committing suicide as assuredly as if we had handed them a gun." Thus, a suicide note is more or less the same as a living will, because it expresses a desire to die. There is no time here to go into the thorny problem of whether there is, in the end, a difference

between killing and allowing to die. I am convinced that there is such a difference, although I do not hold that the difference is in every case ethically determinative. It must be enough here to say that the US Supreme Court decisions on physician-assisted suicide upheld that difference as legally significant. It also seems apparent to me that people who write advance treatment directives do not thereby express a desire to die, as Kilcullen implies. What they say, in effect, is “don’t do stupid stuff to me!” That is very different. Thus, it seems to me that the suicide note cannot be accepted as testimony of Harry’s rational wishes about life.

However, it does tell us something. It tells us that in Harry’s depressed state he wanted to die. At the least, then, it tells us that we have no evidence that, in his present horribly reduced circumstances, he would have wanted to live. Although we do not know what he might have thought about life when freed from his presumed depression, we know that we do not know that he would have wanted aggressive medical treatment in his present condition. This is not much, but it is something. It means that there is no evidence to support a substituted judgment decision favouring continued life-sustaining treatment. It is here, I think, that Donald Chalfin and Cory Franklin err. Having correctly concluded that the note cannot in any sense be considered a living will, they seem then to argue that Harry must therefore be kept alive. (I say ‘seem’ because it is not entirely clear to me that they want this to be Harry’s permanent state. Their last sentence speaks of ‘investigative options’ and suggests that, after these are exhausted, a ‘different course’ might be possible. My problem with this is that they have earlier concluded that Harry’s condition is such that “Meaningful cognition and basic human interaction will be lost forever.” If this is the case, what would the investigative options tell us? I return to these areas in the next section.) This, I think, is the wrong conclusion to draw. The lack of a living will does not mean that Harry would want aggressive treatment in permanently terrible circumstances. It simply means there is not enough evidence to know what he would have wanted. Also, the four reasons that Chalfin and Franklin give for society to override patient autonomy are apt indeed in the prevention of suicide and in other circumstances as well. However, in the present case the American ethical and legal consensus is that the state’s interest in preserving life is outweighed by Harry’s condition. There comes a time when it is no longer morally or legally mandatory to preserve life.

Also, in most jurisdictions this time can come even in the absence of clarity about the patient’s wishes. If Harry is unfortunate enough to live in a state where clear and convincing evidence is required of his wishes before treatment can be withdrawn, then we do not have such

evidence, but in all other jurisdictions our lack of evidence to the contrary at least allows us to assume that we may consider withdrawal.

### **The substantive issue – what to do?**

Harry’s attending physicians are (probably) substantively right. As all of the discussants except Chalfin and Franklin – and, in one respect, Crippen – agree, Harry should be given palliative care and allowed to die. I do not think that the cause of his present condition is of much relevance in reaching this conclusion. It may indeed distract us. Depending on our attitudes about suicide, we might be tempted to do more or less to keep him alive than we would for a similar patient shot in a robbery. This, after all, is the key to the case. We have a patient before us with a (probably) terribly bleak prognosis. The physicians can keep him alive, but he will (probably) never again speak, eat, or interact in any meaningful way with his environment. In short, Harry is (probably) permanently unable to carry on the basic purposes of human life. The treatment that he is getting is, as Whetstine correctly points out, ethically optional. I think it stands on the ‘stupid’ end of the ‘optional’ spectrum. We should stop doing it.

Whetstine is exactly right in her analysis of what ‘ordinary’ and ‘extraordinary’ mean in this context. Her response to Crippen’s suggestion that “if Harry survives off the vent” he would give him a permanent feeding tube is quite correct. In Harry’s condition the determining factor is not the complexity or the cost of the treatment modality. The fact is that Harry will (probably) not benefit from any of it. So turn it off (except, obviously, pain management), and do not start anything new: no feeding tube, no antibiotics – ‘no extraordinary means’.

However, there is the ‘probably’. Only Stephen Streat seems to have worried that the case at it stands may not present a clear prognosis. He wants to wait a few days and then, if the assessment confirms permanent brain damage, withdraw life-sustaining therapies. This appears to me the proper answer to the substantive question.

### **The procedural question – who does it and how?**

The case says little about Harry’s friends or family. What about parents, ex-wives, siblings? Try to find them. This may, of course, cause delay. Harry would be legally entitled to insist on treatment if he were able to do that. His family might make that very decision. American case law tends to permit surrogates to insist on life-sustaining treatment, even when physicians or ‘reasonable people’ would not want it. Continued treatment for Harry is not medically futile; it keeps him alive. Thus, it may be that Harry’s family will not let the treatment stop, but American law still wants a surrogate decision-maker for Harry, and the doctors have to try to find some family to do this.

Assuming that no family members are available (or none of them are willing) to act in this capacity, then hospitals differ about whether it is necessary to go to court to get a guardian appointed. That is the traditional way to do it, but a number of hospitals have inaugurated policies in the very rare case in which there is no surrogate of allowing the decision to forgo treatment to be made at the bedside after a rigorous clinical (again, see Streat's comments) and ethical investigation. This is sensible. The court is not the place to make decisions like this, and court-appointed guardians are not necessary. There is also a problem of cost and one of conflict of interest if one of the hospital staff is appointed. In cases like these, the decision can properly be made without these added difficulties and delays.

I end by underlining an important point made in the discussion that is often overlooked. Advance treatment directives are seldom if ever sufficient in themselves. As Truog states, they almost always require interpretation. That is why proxy directives are so often of greater help in ambiguous situations. Someone has to do the interpreting, and American law assumes the best someone would know what the patient wants and would act in the patient's best interests. Even though these standards (substituted judgement and best interests, or subjective and objective standards) are imperfect, they are the best we have. We might like to eliminate uncertainty, but complex cases are uncertain. We do the best we can. In Harry's case we make sure of the prognosis and then (assuming the agreement of any legitimate surrogate) we stop doing stupid stuff to him.

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