End of Life Decision-making, Policy and the Criminal Justice System: Untrained Carers Assuming Responsibility [UCARes] and Their Uncertain Legal Liabilities

Hazel Biggs and Robin Mackenzie

Genomics, Society and Policy 2 (1) pp 118 – 128 2006

Not Published Version

Abstract: This article will explore some previously unrecognised legal and ethical issues associated with informal care-giving and criminal justice in the context of end of life decision-making. It was prompted by a recent case in Leeds Crown Court, which raises important issues for the people who care for their loved ones at home and for the criminal justice system more generally. Government figures estimate that over 5.2 million Britons are responsible for the care of relatives or loved ones. In order to evaluate some of the ways in which they might find themselves exposed to unexpected criminal liability we have characterised this group as untrained carers who assume responsibility (UCARes).

Keywords: n/a

Introduction

The relationship between genomics, genetic disabilities, and legal liabilities has been most commonly explored in relation to choice in reproduction and services provided for the impaired and their carers. The intersection between genomics, genetic impairment and the criminal justice system has remained relatively unexplored. This article seeks to bring to public attention problematic situations which are likely to impact upon an increasing proportion of the population. In 2001 Government figures estimated that approximately 5.2 million people were providing informal care in England and Wales, which amounts to one in ten of the population. These figures exclude parents caring for non-disabled children. Such informal carers are not care-workers or staff employed to provide care, but people who look after relatives or friends needing care and support due to age, infirmity, physical or mental illness or disability. They may be elderly or unwell themselves or possibly even under the age of 18 and providing care for an older family member. Another way of looking at this is that at least another one in ten of the population is being informally cared for by an untrained voluntary carer. Such untrained carers who assume responsibility for the health and well-being of familial or emotional relationships (UCARes) form the focus of this article.

Inevitably, more of us will be involved in these types of relationships as a higher proportion of the population is made up of the elderly. In addition, in general British
people are tending to live for longer in better physical health, but remain subject to mental infirmities induced by genetic susceptibilities, such as Alzheimer's. Evidence of genomic vulnerabilities and the part played by inherited factors in illness suggests that many of us with chronic complaints and impairments, as well as the increasing number of number of elderly demented, may be regarded as being genetically compromised and in need of continuing care. This matters because, while the responsibilities and legal liabilities of professional carers are generally well understood, if things go wrong in the informal care setting the cared for may be inadequately protected and UCARes may find themselves exposed to unforeseen legal consequences.

In the UK there has been a long tradition of non-professional caring which today is further encouraged by health policy and economics. Care of the elderly, the infirm and children, has always taken place within the home, relying on the good will and fortitude of genetically related emotional carers. UCAREs have traditionally been women, but demographic and social changes, such as the increased involvement of women in the workforce, have disrupted both the assumptions that underpin the traditional approach and the physical resources to provide adequate care. As a result recent decades witnessed a growth in institutional care for some types of cared for people, most notably the elderly. The proliferation of care homes generated a need for regulation of staff and institutions, resulting in increasing costs, which ultimately has led to a rising charges for the families concerned. Inevitably tensions have developed between the need for outside care and the means to pay for it. In many cases emotional carers find themselves financially burdened by the costs of providing institutional care while others seek to avoid the financial cost by shouldering the physical responsibility themselves by becoming UCAREs.

In the context of end of life decision-making this article will explore some previously unrecognised legal and ethical issues associated with informal care-giving and criminal justice. Drawing on recent court cases involving the care of people with debilitating inherited medical conditions we will consider a detailed hypothetical scenario involving Alice and Benjamin to illustrate some issues associated with UCARes, end of life decision-making and the criminal justice system.

Alice and Benjamin: UCARes and end of life decision making

Alice is caring for Benjamin who suffers from motor neurone disease (MND), which is a degenerative and ultimately fatal inherited condition. In the terminal phases of this condition people often suffer the effects of suffocation and diaphragmatic failure while their mental abilities and awareness remain unimpaired. Benjamin does not wish to die in this way. Ideally he would choose to be assisted to die before he reaches the terminal stages of illness and considers several alternative options, active voluntary euthanasia, assisted suicide or suicide. Each will have an impact on the manner of his dying and the likely criminal justice implications for Alice as his UCARE.

Active voluntary euthanasia is defined as the intentional killing of another person who has requested it and in this case Benjamin might ask Alice to deliberately kill him, to spare him further suffering and the pain and distress of the dying process. Out of compassion many UCAREs have helped their carees to die in this way, but the law is not sympathetic and mercy killing is clearly prohibited in order to protect the vulnerable. Even in the case of medical professionals who have agreed to help their
patients to die ‘the law does not leave it in the hands of doctors, it always treats euthanasia as murder’. Some commentators have recommended legal reform to include a new defence of mercy killing where a carer has been charged with murder for allegedly killing a patient at her or his request, but to date the law remains unchanged. Benjamin’s condition is such that eventually he will be unable to physically commit suicide himself and may require, and seek active assistance from Alice. For example, Alice might simply hand Benjamin an overdose of medication or may prepare a fatal potion at his instigation because he no longer has sufficient motor co-ordination to do so himself. However, at present assisting suicide is contrary to the Suicide Act 1961, which makes it a crime to ‘aid, abet, counsel or procure the suicide of another’. This means that any action Alice takes to help Benjamin commit suicide could result in criminal prosecution which, if she is convicted, is punishable by up to 14 years imprisonment. Diane Pretty (also an MND sufferer) recently challenged the United Kingdom’s prohibition on assisted suicide in the European Court of Human Rights but was unsuccessful, despite the fact other European jurisdictions have a more liberal approach to assisted suicide.

In the wake of Diane Pretty’s death the Assisted Dying for the Terminally Ill Bill 2005 has been introduced to the House of Lords as a Private Members Bill. When originally presented in 2004, the Bill included a provision for active voluntary euthanasia in certain circumstances but its amended form will allow only assisted suicide. Should it become law patients seeking assisted suicide under the Bill will have to meet stringent qualifying criteria and a variety of safeguards are incorporated. However, at present the Bill is still undergoing Parliamentary scrutiny and is by no means guaranteed to reach the statute books. It will therefore not help Benjamin if he seeks assisted dying. While assisted suicide remains illegal in the United Kingdom it is legally permitted elsewhere in Europe, most notably in the Netherlands, but people from other parts of the world may not lawfully take advantage of this. However, the law in Switzerland allows citizens from outside the country to avail themselves of assisted suicide services. To date in excess of 70 British nationals have done so and, were he well enough to travel Benjamin could join their ranks. Were he to take this option it is likely that he would ask Alice accompany him and that she would wish to do so, which might expose her to criminal liability.

After Reginald Crewe travelled to Switzerland for assisted suicide accompanied and assisted by his wife and daughter the Crown Prosecution Service (CPS) deliberated for eight months before deciding that their prosecution would not be in the public interest. Thereafter the Director of Public Prosecutions was called upon to issue new guidance on whether and when prosecutions should be brought in these circumstances, but it is reported that there are currently no plans to do so. None the less, it was recently reported that the family (UCARes) of Dr Anne Turner, who also travelled to Switzerland to receive assisted suicide, have been questioned by police about their involvement. No charges have yet been bought.

Given the possibility of exposing Alice to the rigours of the criminal justice system if he involves her in either active voluntary euthanasia or in assisting his suicide, Benjamin might instead decide to take his own life before he becomes too infirm to do so. Here UCARes may unwittingly find themselves in a precarious legal position which has hitherto been unrecognised. The remainder of this article will address this issue.
If, in this hypothetical scenario, Benjamin does decide to commit suicide there are a range of situations that might give rise to criminal liability for Alice. For instance, any involvement Alice has in Benjamin’s decision to end his life could mean that she will be implicated for assisting his suicide as discussed above. Depending on the circumstances however, there are other ways in which she could be found criminally liable and it is these we now seek to explore.

R v Anderson: UCARes and uncertainties in the law

The recent case of R v Anderson (unreported) Leeds Crown Court April 2005 exemplifies the position that Alice might find herself in with regard to the application of manslaughter by omission involving UCARes. There, like Benjamin, the husband was suffering from a debilitating but not immediately life limiting condition, the difference being that the husband in Anderson had M. E. or chronic fatigue syndrome. He had ‘abnormal chronic anxiety’ about his health, had made repeated suicide attempts and been admitted to hospital for treatment on two previous occasions as a consequence. Respecting her husband’s wishes, his wife, his UCARE, deliberately failed to call the emergency services despite knowing that her husband had taken an overdose of morphine with the intention of ending his life. After he died she was tried and acquitted of his manslaughter. During the trial it emerged that she had stayed with him throughout the night and only summoned help some two hours after his final breath. The central issue in court was whether she had a legal duty to act in these circumstances, as the existence of such a duty that she had neglected to perform could render her criminally responsible for his death. Alice, and other UCARes could encounter a similar scenario if their loved ones inform them of their intentions and their desire to commit suicide in order to hasten their deaths and to avoid terminal suffering.

In the context of unqualified carers supporting adult dependants at home the junction between end of life decision making and manslaughter by neglect is fraught with difficulties over the just assignment of legal responsibility. A string of criminal cases has addressed a range of factual situations involving UCARes with a variety of charges and outcomes. Other commentators have identified a certain lack of precision and perhaps inconsistency in the application of the law in this area but, despite this wide ranging academic debate, the uncertainty remains in relation to the group we have characterised as UCARes. In addition recent high profile cases concerning medical decisions at the end of life, may add to the uncertainty of a UCARE over how to respond should their charges purposefully put their lives at risk while insisting that they would also reject life saving medical intervention. In medical law the autonomous rights of competent patients to refuse care is revered but in this environment it conflicts with the aim of the criminal law to protect vulnerable people from abuse through the offence of manslaughter by omission. The tensions between these two related areas of law are likely to be beyond the comprehension of an unqualified carer.

It is of course essential that the state protects the interests of those who are unable to look after themselves, and manslaughter by neglect is in general an appropriate mechanism through which to achieve this. More specifically, where the wrong doer is a professional person whose duty to the patient is readily established, criminal sanction is the most appropriate response when conduct falls very far below an accepted standard. Similarly, where a non-professional carer has intentionally caused the death of a vulnerable person in their care through deliberate omission, a murder charge may
even be appropriate.\textsuperscript{21} Alice is not in this position, but she, and other UCARes, may still be unjustly exposed to the potential of criminal conviction because they have assumed a responsibility to care for a loved one.

If a UCARE like Alice declines to take action and their charge dies the nature of any criminal liability and how far it extends turns on whether or not the UCARE had a legal duty to act in the circumstances. There are various ways in which such a duty can arise.\textsuperscript{22} The most likely roots of obligation here are associated with the special relationship between spouses and the fact that by her conduct in providing support Alice will have assumed a duty to care for her infirm husband. The duty arises under the civil law. If the duty is neglected, resulting in death, it gives rise to criminal liability. As Lord Mackay explains;

‘...the ordinary principles of the law of negligence apply to ascertain whether or not the defendant has been in breach of a duty of care towards the victim who has died. If such a breach of duty is established the next question is whether that breach of duty caused the death of the victim.’\textsuperscript{23}

However, in addition to this, we argue that it is possible to regard UCARes as owing a duty to those they care for over and above the ordinary duty of care, that is, a moral duty to respect the autonomous wishes of their caree. This moral duty may conflict with the established legal duty to preserve life if the cared for person desires to die and declines assistance. For example, in Anderson the UCARE asserted that she felt obliged to respect her husband’s wish to die and therefore decided not to call an ambulance.

‘I searched my conscience and the act I did that night was for him, not me, he wanted to go… what I did that night was an act of love and an act of kindness … it was very difficult to face a prosecution for loving someone, because that’s all I did that night.’\textsuperscript{24}

In this way Jill Anderson reveals that she believed she owed a higher moral duty to her husband, which led her to act in the way she did.\textsuperscript{25} Nonetheless authorities demonstrate that legal liability has been imposed in similar situations in a number of cases despite the defendants’ appeal to a higher moral duty.

**UCARes and their duty of care**

In Nicholls,\textsuperscript{26} the first case that decided such a duty could arise in the absence of a contractual relationship, Bret J directed the jury that,

‘if a grown up person chooses to undertake the charge of a human creature helpless either from infancy, simplicity or other infirmity, he is bound to exercise that charge without (at all events) wicked negligence; and if a person who has chosen to take charge of a helpless creature lets it die by wicked negligence, that person is guilty of manslaughter.’

The direction was followed in an array of subsequent cases\textsuperscript{27} establishing that a duty may arise in these circumstances without clearly specifying the parameters of when the
duty arises and how far it extends.

More recently Smith\textsuperscript{28} confirmed that a husband had a duty to care for his wife’s health. In this manslaughter prosecution it was questioned whether a failure to call a doctor in the face of the wife’s refusal amounted to a ‘reckless disregard’ of the duty of care. As in Anderson, Smith was aware that he would be subjecting his spouse to a serious risk to her health if he failed to get help but none the less he acceded to her wishes, resulting in her death. In the Anderson case, and in our hypothetical, it is questionable whether the UCARE is guilty of ‘wicked negligence’ in these terms because, at least at the outset, the caree might not be regarded as a helpless creature. Rather, the cared person could be regarded as an autonomous person refusing future medical intervention.

Assuming that the UCARE becomes aware of the suicide attempt before the caree actually succumbs, there is likely to be a point in time where loss of consciousness renders them as a helpless creature. It seems clear that ordinarily, even if it could be argued that there was no duty in existence up until this point, a duty would arise once the caree becomes so ill that death is inevitable in the absence of medical treatment. In Smith the judge questioned whether a person who becomes desperately unwell ought always to be regarded as a helpless creature for these purposes, even where the ill person has objected to medical intervention. However, the matter was left for the jury to determine with regard to whether the deceased person could be supposed to have the capacity to decide to refuse treatment. Subsequent cases in the medical law arena,\textsuperscript{29} where it has been held that even an irrational decision must be respected if the individual has capacity, have clarified the role of autonomy and self-determination.

Where the alleged victim has caused his own predicament, as would be the case where someone like Benjamin deliberately takes an overdose in order to kill himself, he may not represent the archetypal helpless creature and the duty on his wife may therefore be different. In this case, Benjamin would appear to be acting on a settled wish to die and to expect that his wife would not overrule that autonomous choice. In accordance with this, and because of her relationship with her husband, once Alice became aware of the inevitability of his death, her refraining from summoning medical assistance would seem legitimate if her overriding concern were to be to respect his wish and allow him to die and release him from suffering. As the defendant in Anderson claimed,

‘… of course, I never thought of the consequences for myself, I only thought about him.’\textsuperscript{30}

If the UCARE’s duty is constructed according to the ordinary objective criteria and Benjamin is categorised as a helpless creature it is plain that Alice would be obliged to call for assistance. But, if the surrounding circumstances of their particular relationship and his intention to die are factored into the equation, then subjectively her duty is more ambiguous. A charge of manslaughter is appropriate where the conduct of the accused falls so far below what was expected that a severe breach of duty has occurred, but a UCARE like Alice is not necessarily in that position. Instead, in omitting to seek medical assistance this carer could be said to have acted according to a higher moral obligation owed to the person cared for.
UCARes: the criminal justice system

The criminal justice system is concerned with safeguarding against evil intent and protecting the innocent and helpless. There are many cases involving manslaughter by neglect where clear evidence of evil wrongdoing and deliberate infliction of harm to a helpless victim have resulted in appropriate conviction. For example, in Bonnyman the husband of a drug addicted woman acted to prevent proper medical examination and treatment of his emaciated wife who was described in court as ‘as helpless as a person could be to deliver herself from this pit into which she had fallen.’ The husband claimed that he was prevented from seeking help because his wife was ‘stubborn and would not let him help her’ but the court found this incredible on the facts and rightly determined that ‘the plain duty of the appellant was to have given her aid and treatment which he withheld’. Bonnyman’s false assertion that his wife refused medical intervention could not excuse his deplorable conduct because she was clearly in a helpless state and deserved to be cared for by those who owed her a duty.

Although, like Bonnyman, cases involving UCARes concern deliberate decisions not to seek medical assistance, they may be distinguished because of the lack of evil intent. Here the UCARE acts according to what they regard as a higher moral duty to respect the wish of their charge and allow them to die. In addition, as we have argued the ‘victim’ is not a ‘helpless creature’ but is regarded by the UCARE as a person capable of making a rational choice to die and acting upon it. We would suggest therefore that where the person is self-determining and committing a rational suicide the ordinary principles do not apply. This is in accordance with a view previously promulgated by Glanville Williams when commenting on a review of potential reform of the law of manslaughter. Confirming that the duty of care is generated by helplessness he stated that, ‘the person to whom the duty is owed must be unable to perform it himself …’ and also that,

‘[Secondly] the code should preserve the caree’s right of autonomy (self determination). No-one should be criminally liable for failing to provide an adult with a service he does not want – still less for failing to force it on him.’

The case of Robb examined similar issues in a case concerning a hunger striker and confirmed that where an adult of sound mind refuses all treatment and nutrition those wishes must be respected, regardless of whether the reasons for doing so are rational or irrational. The rule applies where the individual is being cared for by professionals since the person’s autonomous refusal will absolve the professional carer of responsibility. In other words, the carer will be released from any duty owed to the caree. This has particular resonance for UCAREs who feel a specific responsibility to respect the wishes of those they care for, and further informs our claim that the duty of care should be interpreted subjectively in these cases. In the fraught medico-legal environment where a UCARE fails to summon medical assistance because their charge has declined such intervention the position is complex. The UCARE becomes the guardian of the caree’s wishes so that the carer is not simply released from the obligations of care but sees the omission as actively fulfilling their higher duty. The carer would then be effectively saving the charge from the harm associated with overriding their autonomy. In normal circumstances the criminal law would assume that by failing to intervene and save a person like Benjamin from the consequences of his suicide a UCARE has caused
harm. Yet if the caree had a genuine wish to die he would perceive an intervention to keep him alive as harmful.36 Those whose autonomous desire not to receive medical treatment has been wrongfully overridden have received damages in recognition of the harm done to them.37 For some people ignoring their wish to die amounts to a harm worse than death,

“In most instances of homicide death is the harm caused by the conduct of the accused. With euthanasia, the indignity of a living death in a persistent vegetative state, or the protracted dying process associated with terminal disease can appear more harmful than death itself.”38

Aside from these issues associated with the establishment of a legal duty of care, before a criminal conviction can be secured the prosecution would also need to ascertain that Alice’s conduct had caused Benjamin’s death. It was confirmed in Adomako that once ‘a breach of duty is established the next question is whether that breach of duty caused the death of the victim.’39

In the criminal law there is ‘considerable uncertainty over the relationship between causation and omissions.’40 On one reading of the facts in this hypothetical scenario, if Benjamin dies after Alice omits to seek assistance that could rescue him following his suicide, her conduct appears to directly result in her husband’s death. But for her failure to arrange medical intervention, he would not have died. However, an alternative interpretation suggests that if a duty arises at all, it does not arise until Benjamin becomes a helpless creature, by which time his death is inevitable and her failure to act has no influence on the chain of causation.

Alternatively, in the context of a UCARE who is responding to the autonomous wishes of a person in their charge it is interesting to consider what might happen if Alice had summoned help. If Benjamin were to be admitted to hospital before becoming unconscious he may well decide to refuse treatment. If, in these circumstances he was regarded as competent to make such a decision then, following dicta in recent medical law cases,41 his wish would have to be respected. The result would be that he would have died. Alice would not have caused his death and would not be liable. A different outcome can be anticipated however if Benjamin were to be taken to hospital in an unconscious state. Then it is most likely that he would receive emergency treatment with the health professionals acting in keeping with their professional and legal duty to treat him according to his best interests as the extremity of the situation dictated.

**Conclusion**

One way of looking at these facts suggests if a UCARE like Alice prevented the administration of medical assistance that could save life they would have caused the death and thus be susceptible to criminal sanction. However, from another perspective the issue is not so straightforward. Either no duty arises or it does not arise until the caree becomes helpless, by which time death is unavoidable and then causation is not an issue because her omission, or failure to act, could have no impact. Clearly, as there are so many alternative legal constructions that might apply in this context UCAREs can be forgiven for confusion surrounding how far their duty extends towards those they care for and perhaps for neglecting their duty given this uncertainty. UCAREs are not
benefited by the training or institutional support available to medical professionals and are consequently exposed to a greater risk of criminal liability, which leaves them vulnerable to charges of manslaughter by neglect. This seems inappropriate given the reluctance to bring prosecutions in various situations like death tourism and the possible legalisation of assisted suicide for the terminally ill, both of which evidence a shift in contemporary notions of what is justifiable.

The concerns raised in this paper may initially appear to be of limited relevance and focused on a very narrow point of law, but as they potentially affect around one fifth of the population they cannot be regarded as insignificant. Whereas ignorance of the law is no defence to criminal liability, uncertainties within the law must be resolved before criminal justice system sanctions come into play. The penalties associated with assisting suicide, manslaughter and breaches of the duties of care are clear in relation to healthcare professionals. Yet the lawful boundaries between UCARes’ duty of care, our right to refuse medical treatment and the higher moral duties we feel in relation to our loved ones are inchoate and uncertain. Equally, the need for the criminal justice system to preserve ‘helpless creatures’ vulnerable to the intolerable cruelties of uncaring UCARes is clear. These issues need to be considered in the volatile context of end of life decision-making, death tourism and calls for the legalisation of assisted dying to ensure that both UCARes and those they care for are adequately and appropriately protected.

1 The authors would like to acknowledge the very helpful comments of Dr Matthew Weait on an earlier draft of this article, along with those of the anonymous reviewers of Genomics, Society and Policy.
4 Untrained Carer Assuming Responsibility.
5 For example, unpaid support of the elderly is an accepted part of modern family life, See M. Brogden, 2001. Geronticide: Killing the Elderly. London, Jessica Kingsley.
6 Similar issues have been discussed in Pretty v UK (Application 2346/02) [2002] 2FCR 97, R (on the application of Burke) v General Medical Council [2005] 3 WLR 1132, R v Wragg December 2005 Lewes Crown Court, unreported and the recent case of Dr Anne Turner.
7 In the USA this is known as amyotrophic lateral sclerosis.
8 There are numerous examples of UCARes acting in this way, the most recent reported case being that of Maureen Messent who has admitted killing her elderly aunt 40 years ago. See http://news.bbc.co.uk/1/hi/england/4692320.stm last accessed 12th March 2006.
11 So-called mercy killings also occur where a UCARe deliberately ends the life of a person in their care who either does not or cannot request it. Frequently such cases involve children with terminal or incurable genetic conditions, as in the case of Andrew Wragg, supra n. 5, but these cases are outside the focus of this article.
12 Suicide Act 1961, s2 (1).


20. Examples might include situations where the defendant has deliberately exposed the victim to the harm which subsequently arose due to the neglect as in R v Sogunro [1997] Crim App. Rep. 2 (S.) 89 where the victim was locked in a room by the defendant and subsequently deprived of food.

22. For example, by virtue of a contract, Pitwood (1902) 19 TLR 37, because there is a special relationship, Smith (1979) Crim Law Rev 251, through the voluntary assumption of a duty, Stone and Dobinson (1977) 2 All ER 341, by statute Lowe (1973) 1 All ER 805, and, where the defendant has created a dangerous situation, Miller (1983) 1 All ER 978.


25. Her comments are redolent of those put forward by women activists who damaged a hawk fighter jet in protest against arms dealing. The women claimed in their defence that they had a higher moral duty to protect those in East Timor who would become innocent victims had the planes been exported. They were acquitted. See, H. O'Shaughnessy, ‘£1.5m Hawk Attack Women Freed’ The Independent, 31 July 1996, and an article written by one of the protestors, A. Zelter. Civil Society and Global Responsibility: The Arms Trade and East Timor. International Relations 2004; 18: 125-140.

26. R v Nichols (1874) 13 Cox 75.

34. Idem.
37. Re B (Adult Refusal of Medical Treatment) [2002] 2 All ER 449.