

Where are the carers in healthcare law and ethics?*

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The work of carers is too often unvalued and unrecognised. This paper seeks to demonstrate some of the ways in which law and traditional medical ethics overlook the interests of carers and the importance of their work. It argues that this is, in part, due to the individualistic ethic that has come to dominate legal and ethical discourse about medicine. It recommends an approach based on an ethic of care that seeks to promote and protect just relationships of care, rather than an individualised model of rights.

INTRODUCTION

No one would dare set the following question in an examination paper for medical law and ethics:

‘Michael is 65 and needs a hip replacement. Without it he will have very limited movement. His doctor explains the options and recommends a hip replacement. Michael decides not to go through with the operation. Is the doctor entitled legally or ethically to force the operation upon Michael?’

The answer is far too easy. The law is clear: it is unlawful to impose medical treatment on a competent person without their consent. The ethics are clear too: the principle of autonomy gives the patient an absolute right to refuse treatment.¹

My argument will be that the case should not necessarily be regarded as that straightforward. Important issues are hidden. Where are the interests of his partner and his family? Where are the carers? They have become ‘ignored and invisible’.² This paper will seek to demonstrate how easy it is and how common it is for legal and ethical issues in healthcare to consider just the isolated patient and the medical professionals. It is extraordinary that despite the central role that unpaid carers play in the healthcare of the nation, they are rarely, if ever, mentioned in textbooks or articles on medical law or ethics.³

The first part of this paper will show that the interests of carers are often overlooked and, as a result, carers receive a poor deal. This is hardly controversial. Just a few

* A version of this paper was given at a seminar arranged by the Royal Institute of Philosophy at the Centre for Professional Ethics, University of Keele. I am grateful to the participants for their comments and those of two anonymous referees and Sally Sheldon.

1. E Jackson *Medical Law* (Oxford: Oxford University Press, 2006) ch 4. For work on carers from sociological perspectives, see J Read *Disability, the Family and Society: Listening to Mothers* (Buckingham: Open University Press, 2000); J Read and L Clements *Disabled Children and the Law: Research and Good Practice* (London: Jessica Kingsley, 2001); and K Stalker (ed) *Reconceptualising Work with ‘Carers’* (London, Jessica Kingsley, 2002).

2. M Henwood *Ignored and Invisible* (London: Carers’ National Association, 1998).

3. Not even, unfortunately, in J Herring *Medical Law and Ethics* (Oxford: Oxford University Press, 2006).

months ago the Commission for Social Care Inspection stated that 'Carers need support. Councils need to rethink their approach to the development of services to support carers. Currently little support is available, and what is available is extremely limited, both in quantity and quality'.⁴

The second part of the paper will consider why it is that carers appear to be so easily ignored. Is it not blatantly obvious that carers' interests are important? Indeed, the government had announced a *National Strategy of Carers*, with the Prime Minister declaring:

'What carers do should be properly recognised, and properly supported – and the Government should play its part. Carers should be able to take pride in what they do. And in turn, we should take pride in carers. I am determined to see that they do – and that we all do.'⁵

This paper will argue that the fact that the interests of carers are so easily lost is not simply the story of another disadvantaged group within a society whose political muscle is not sufficiently strong to bend the government's ear. It may be that in part, but it is also due to the way that medical law and ethics tends to view patients and medical professionals as isolated individuals.

Before moving on we need to consider the meaning of the word 'carer'. The government has suggested the following: 'By carers we mean people who look after a relative or friend who needs support because of age, physical or learning disability or illness, including mental illness'.⁶ This definition would include parents, although that was probably not the government's intention.⁷ Generally, the term carer is taken to exclude parents caring for able-bodied children and paid carers.⁸ Whether the term carer should include parents or paid carers raises a number of interesting issues. For the purposes of this paper carer will be taken to exclude those groups.

SOME FACTS

Let us start with some facts about carers. The 2001 census indicated that there are about 6 million carers in the UK.⁹ The General Household Survey estimates there are over 7 million.¹⁰ Carers UK state that three in every five people will become a carer at some point in their lives.¹¹ The 2001 census revealed that 58% of carers are women.

4. Commission for Social Care Inspection *The State of Social Care in England 2004–5* (London: Commission for Social Care Inspection, 2005).

5. Department of Health *Caring About Carers* (London: Department of Health, 2005) p 1.

6. Ibid, p 1. C Ungerson 'Cash in care' in M Harrington Meyer *Care Work: Gender Class and the Welfare State* (London: Routledge, 2000) p 68 states that the government has paid only 'lip service' to promoting the interests of carers.

7. Immediately following this definition, the government gives the number of carers at 5.2 million; they cannot, therefore, have intended their definition to extend to parents.

8. See, for example, the definition of carers in Carers UK *Facts About Carers* (London: Carers UK, 2005) p 1. Indeed most legislation dealing with carers excludes paid carers: L Clements *Carers and the Law* (London: Carers UK, 2005) para 2.3.

9. Carers UK, above n 8, p 1.

10. J Maher and H Green *Carers 2000* (London: Office for National Statistics, The Stationery Office, 2001).

11. Carers UK *Without Us...? Calculating the Value of Carers' Support* (London: Carers UK, 2002).

Indeed, one in four women aged 50–59 are involved in caring.¹² There are 174,995 young people under the age of 18 involved in caring.¹³

Despite the joys that caring can bring, it also brings with it significant disadvantages.¹⁴

- Carers often suffer poverty. Carers UK claim that 77% of carers are financially worse off since becoming a carer, and many end up in poverty during retirement as a result of not being able to work.¹⁵ It has been claimed that seven out of ten older carers are unable to afford adequate heating or clothing.¹⁶ Although there is some benefit provision, it often goes unclaimed, with carers not claiming nearly £750 million per year.¹⁷
- The health of carers suffers. A survey by Carers UK found that those caring for 50 hours a week or more were twice as likely to be ‘not in good health’ as those not caring.¹⁸ Four out of ten carers suffer physical effects from caring such as back pain or other injury.¹⁹ Almost nine out of ten carers in a survey reported that they felt stress, anxiety, depression or loss of sleep, due to being a carer.²⁰ Carers who provide substantial amounts of care are said to be twice as likely to have mental health problems than those who are not providing such care.²¹
- In a wider sense, carers experience social isolation and exclusion, from a failure to recognise their role in society. A recent survey of carers for an ITV News investigation found 21% of carers saying life was a constant struggle.²²
- There are particular issues surrounding children and young people who undertake caring responsibilities.²³ It is not surprising that young carers are disadvantaged in educational and social terms. A recent report found that 27% of young carers of secondary school aged had missed school or experienced educational difficulties.²⁴

All of this, yet carers provide an essential role to society.²⁵ It has been claimed that the value of the care provided is a staggering £57.4 billion per year, the equivalent

12. P Bywaters and A Harris ‘Supporting carers: is practice still sexist?’ (1998) 6 *Health and Social Care in the Community* 458.

13. Maher and Green, above n 10.

14. M Hirst ‘Carer distress: a prospective, population-based study’ (2005) 61 *Social Science & Medicine* 697.

15. Carers UK *Carers UK Welcomes White Paper* (London: Carers UK, 2006).

16. ‘Carers missing £750m benefits’ *BBC News* online 2 December 2005.

17. *Ibid.*

18. M Hirst *Hearts and Minds: The Health Effects of Caring* (London: Carers UK, 2004).

19. *Ibid.*

20. B Keeley and M Clarke *Carers Speak Out Project* (London: Princess Royal Trust for Carers, 2002). See also G Deimling et al ‘Care-related stress. A comparison of spouse and adult-child caregivers in shared and separate households’ (1989) 1 *Journal of Aging and Health* 67.

21. A Marriott et al ‘Effectiveness of cognitive-behavioural family intervention in reducing the burden of care in carers of patients with Alzheimer’s disease’ (2000) 176 *British Journal of Psychiatry* 557.

22. ITV News Special *Who Cares?* broadcast 5 February 2006.

23. A Walker *Young Carers and their Families* (London: HMSO, 1996); C Dearden and S Becker *Young Carers in the UK* (London: Carers UK, 2004).

24. Dearden and Becker, *ibid.*

25. The Princess Royal Trust for Carers *Eight Hours a Day and Taken for Granted* (London: PRTC, 1998); P Smith ‘Elder care, gender, and work: the work–family issue of the 21st century’ (2004) 25 *Berkeley Journal of Employment and Labour Law* 351.

to the spending on the National Health Service (NHS).²⁶ Of course the value of care lies not just in its economic worth. It has almost become a cliché to say that a society should be judged by how it treats its most vulnerable members, but, if this is so, then carers play a central role in one of society's most important tasks.

CARERS BEING OVERLOOKED

Examples will now be given of areas in healthcare law and ethics in which the interests of carers have been overlooked.

Quality Adjusted Life Years

Quality Adjusted Life Years (QALY) is probably the most popular way of analysing the cost-effectiveness of treatments and is widely used in decision making in rationing healthcare. It is used by the National Institute for Health and Clinical Excellence (NICE).²⁷

QALY, as used in rationing decisions, requires an assessment of three factors:

- How many extra years of life will the treatment provide this patient?
- What will the quality of those extra years be?
- How expensive is the treatment?

A treatment that provides a year of perfect health scores as one; however, a year of less than perfect health will score less than one. Death is equivalent to 0. Under QALY, therefore, a treatment that provides a patient with an extra year of perfect health would be preferred to a treatment that provides a patient with an extra year, but a year of pain and low quality of life. A treatment which offered a large number of QALYs for a small amount of money would be highly cost-effective, while one that produced a low number of QALYs for a large amount of money would not be. Someone required to ration health services can therefore examine a range of different services and consider how many QALYs for how much money is possible.

Despite its popularity, QALY is individualistic in focusing just on the impact of the treatment on the individual patient. When considering a patient, the improvement in the patient's quality of life alone is considered and the impact on their carers counts for nothing. It may be that, for example, a drug that prevents incontinence might not hugely improve the quality of life for the patient, but have a dramatic impact on the quality of life for their carer. Yet the impact on the carer would count for nothing in a traditional analysis of QALY.

A particular example of the 'misuse' of QALY is NICE's response to drugs for the treatment of dementia.²⁸ In 2005, NICE proposed that certain drugs should not be authorised for NHS patients because their cost was too high and 'outside the range of cost effectiveness that might be considered appropriate for the NHS'.²⁹ Professor

26. Carers UK, above n 8.

27. J Fox-Rushby *Disability Adjusted Life Years (DALYs) for Decision-Making?* (London: Office of Health Economics, 2002).

28. J Harris 'It's not NICE to discriminate' (2005) 31 *Journal of Medical Ethics* 373.

29. National Institute for Health and Clinical Excellence *Appraisal Consultation Document: Donepezil, Rivastigmine, Galantamine and Memantine for the Treatment of Alzheimer's Disease* (London: NICE, 2005) para 4.3.5.

John Harris, never one to mince his words, comments that 'It is difficult to think of this as anything but wickedness or folly or more likely both'.³⁰ NICE's decision was based on a QALY assessment: the improvement in quality of life for Alzheimer's patients per year was insufficient to justify the expenditure. There are a number of ways NICE's decision could be challenged. Here the focus will be in the absence of any consideration of the burden on those caring for people suffering dementia. The distress of seeing an individual you have loved and is central to your sense of self lose their personality, memory and become, in a sense, a different person is hard to bear. This is particularly so where the disease manifests itself in aggression. Medication that may inhibit the progress of this condition is of huge benefit, not just to the individual patient, but for those caring for him or her.

In January 2006 NICE, acknowledging the controversy that had arisen, revised its decision and issued further guidance. However, NICE rejected the use of Ebixa for late stages of Alzheimer's disease and recommended that anti-cholinesterase treatments³¹ not be available for people with a mild version of the disease. NICE found the clinical benefits of Ebixa for advance Alzheimer's not demonstrated. However, it did support the use of anti-cholinesterase treatment if the condition was not mild. This time, in reaching its conclusions, the Committee did consider the benefit of the treatment to carers. It held:

'The Committee considered that although at any point in time a carer may have a higher utility if they were caring for a person responding to drug treatment than if the person were not on the drug or not responding to the drug, the effect of the drug would be to delay progression of the condition, in which case the carer would still be faced at some time in the future with the same difficulties caused by disease progression. Exceptions could be if the person did not progress to later and more difficult stages of the disease within 5 years or because of death.'³²

The argument is, in effect, that if the carer is going to have the disadvantage of caring for the person suffering from Alzheimer's at some point in time it is of no difference to the carer whether they suffer it now or at some future date. This is, however, to place insufficient weight on the obvious benefit to the carer of delaying the onset of the progression of the illness: the fact that the carer will have more time with their loved one, before the condition takes its toll. The loss of that time, to the carer, is a deep loss – in particular, because the carer in the early months would have the anguish of knowing that the person they are caring for would not be as ill as they are if the drug had been provided.

The NICE report went on to say that the QALY assessment should be conducted from the perspective of the NHS: 'The Committee therefore concluded that it would not be appropriate to include carer costs in the augmented base case or sensitivity analyses on the augmented base case'.³³ So costs to the NHS count, costs to carers do not. Yet the costs to the individual carer are costs to real people whose lives bear the blight of caring. By contrast, any cost to the NHS and society is spread across everyone. To count for nothing the sacrifices of carers and to consider only the monetary loss to the NHS in allocating healthcare resources is unjustifiable. Politically, of course, the approach is understandable. Costs to the NHS are in the public

30. Harris, above n 28.

31. Donepezil, rivastigmine and galantamine.

32. NICE *Donepezil, Galantamine, Rivastigmine (Review) and Memantine for the Treatment of Alzheimer's Disease (Appraisal Consultation)* (London: NICE, 2006) para 4.3.10.2.

33. *Ibid*, para 4.3.10.3.

eye and impact on the sensitive issue of levels of taxation. Costs to carers go unnoticed in the public area, although real enough to those who suffer them, and real enough in their effect on society as a whole.

There is, it must be admitted, a danger in considering the impact of treatments on carers in considering rationing decisions. For example, a person who is cared for by a number of family members will be able to claim a 'larger' loss if s/he is not provided with treatment than a person who lives alone with no one caring for them. Should a person's access to treatment depend on how many people love them? But this concern is, in fact, more to do with a system based on QALYs rather than being about the role of carers. The QALYs approach leads to different treatment based on what might appear to be based on criteria that might be thought to cause unfairness: a person's pain threshold; their life expectancy; their present state of health. Indeed, a popular complaint about QALYs is that it can cause unfair discrimination in treatment based on age. It faces complaints that often face consequentialist approaches to complex issues. My point is that if we are using a consequentialist approach based on QALYs, despite the apparent unfairness that can result, we should include carers in the assessment of the extent to which a treatment improves the quality of lives.

Carers under the law of tort

If A is injured by X's negligence and, as a result, A's partner has to give up work to care for him, it might be expected that the law would say that X has, as a result of her negligence, caused A's partner a loss and is liable to pay him damages. But no. X is liable to pay damages for A's partner's loss, but these are payable to A,³⁴ although A will then hold them on trust for him.

The use of the trust might be thought just a technical issue. After all, at the end of the day, the carer receives the damages and should it matter exactly how the law formulates this? It is suggested that it should matter for two reasons. First, the carer is at the mercy of the claimant suing for damages.³⁵ If the claimant does not wish to sue, for example she cannot face the effort of litigation, the carer has no remedy.³⁶ Secondly, there is the symbolic effect that the carer's identity is subsumed within the identity of the claimant. The loss to the carer is not explicitly acknowledged: the loss is seen as the loss to the claimant who will have to pay for care.

Even where damages are paid, the carer will not necessarily get the actual loss of earnings she has suffered.³⁷ The Law Commission reports that the general approach is to award the amount it would cost to pay for the care on the open market, less one-third. The one-third reduction is to reflect the fact that national insurance and tax costs are not incurred.³⁸ Colin McEachran QC referring to these cases states that gratuitous care is 'grossly undervalued by the courts'.³⁹ It does not necessarily reflect

34. *Hunt v Severs* [1994] 2 All ER 385. A useful summary and discussion of the law is found in the Law Commission *Damages for Personal Injury: Medical, Nursing and Other Expenses; Collateral Benefits* (Report No 262, 1999).

35. Law Commission, *ibid*, para 3.47.

36. S Degeling *Restitutory Rights to Share in Damages* (Cambridge: Cambridge University Press, 2003).

37. B Braithwaite 'The significance of family care for injured people' [2005] *Personal Injury Compensation* 10.

38. Law Commission, *above n 34*, para 3.83.

39. *Ibid*, para 3.84.

the actual loss of income suffered by the carer. It might be said that where the would-be carer is currently earning more than a paid carer would be, the claimant should mitigate the loss and rely on paid care, rather than their high-earning relative or friend providing the care. However, surely it is reasonable to prefer care to be provided by a person close to you.

Supporters of the current tort law approach to carers might argue that it is appropriate because the carer has no 'right to provide care' and so should not be able to seek damages in respect of it.⁴⁰ A carer should not be able to receive damages for care which the injured person may decide they would rather receive from someone else. This argument may have carried weight in the past. But, in these days of structured settlements where damages can be paid in variable instalments over time,⁴¹ the argument is weaker. The instalments can be paid to the person who has been providing care (or is likely to provide care) for the relevant period of time and payments can cease if they stop providing the care.

Removal of incapable people from their carers

When a local authority wishes to take a child into care, a protective order can only be made if the 'threshold criteria' in s 31 of the Children Act 1989 are met, which include a requirement that the child is suffering or likely to suffer significant harm and that is attributable to the care of their parents.⁴² Where a local authority seeks to remove an individual from their home under its powers under the National Assistance Act 1948, s 47⁴³ there are similar provisions. It is necessary to show that the person is suffering from grave chronic disease, or is infirm or 'physically incapacitated', and is living in unsanitary conditions. Further, it is necessary to show that the person is unable to care for herself and is not receiving proper care and attention from others, and that her removal is necessary in her own interests or to prevent injury or serious nuisance to others. However, it is open to a local authority to rely on the inherent jurisdiction to remove an incompetent individual from their carer. In these cases, there are no such hurdles to overcome.

In *A Local Authority v Mr BS*,⁴⁴ Ms S, aged 33, suffered from a moderate/severe learning disability and atypical autism and epilepsy. She lacked capacity to decide where she should live and who should provide care for her. Since S's mother's death, Mr S, her father, had been her sole carer, assisted by some privately arranged support workers. In November 2002, there was an allegation that Mr S struck S and this led the local authority to institute proceedings to protect S. Under the inherent jurisdiction⁴⁵ S was placed in a residential placement and contact between S and Mr S was limited to supervised contact.

What is most notable is that, in deciding whether such orders should continue, Wall J distinguished cases such as *BS* with a child being removed into care. Remarkably, Wall J did not even think there was a presumption that an incapable person was best cared for by the person who had been caring for them (in this case) for the past

40. I am grateful to an anonymous reviewer for this point.

41. Damages Act 1996, s 2.

42. Children Act 1989, s 31.

43. As amended by the National Assistance Act 1951.

44. [2003] EWHC 1909 (Admin), [2003] 2 FLR 1235.

45. *Re F (Adult: Court's Jurisdiction)* [2000] 2 FLR 512.

33 years.⁴⁶ Of particular concern are the following reasons which it might be thought could be used against many carers of vulnerable people:

‘On the debit side is the fact that he is now rising 66. He had diabetes and arthritis. He will undoubtedly find it increasingly difficult to care for S as he grows older, and he does not really have any practical contingency plan were he to fall ill . . . Also into the equation inevitably falls a comparison with what the two proposed homes offer to meet S’s needs. The proposed local authority accommodation offers what is, in effect, purpose built accommodation and staffing to meet S’s needs. Furthermore, it offers for her not only the prospect of more social living amongst people of her own age, but facilities which will enable her father and siblings to visit.’⁴⁷

These comments are likely to be true for nearly all parents caring for their disabled adult children. These carers are likely to be older and with some health problems and the contrast between the ‘social living’ and a private home will always be there. The contrast between the protection offered parents whose minor children cannot be removed without the strongest justification and parents whose adult children can be removed if it is assessed to be in their best interests is striking. This is not to say that there should be a direct analogy between the position of a parent and a carer. However, what these decisions do indicate is a lack of proper respect for carers and their role. Luke Clements argues (writing about *A Local Authority v Mr BS* and *Sheffield CC v S*⁴⁸):

‘These two judgements accord, therefore, no formal worth to a family or caring relationship – in the sense that they are deemed to have any inherent value. The view that emerges is that the courts will not credit such relationships with any value – unless it is made out by evidence, and it is then to be recorded as a positive or a negative on the ledger sheet.’⁴⁹

Human Tissue Act 2004

The Human Tissue Act 2004 provides for ‘appropriate consent’ to be required in relation to certain activities undertaken on to the body or material from a corpse. The Act is complex, but broadly speaking the deceased person could have given consent, or someone who is appointed by that person can.⁵⁰ If neither of these provisions applies then it is the person who is highest up the following list of ‘qualifying relationships’:

1. spouse or partner;
2. parent or child;
3. brother or sister;
4. grandparent or grandchild;
5. child of a person falling within paragraph (c);
6. stepfather or stepmother;

46. Ibid, para [22].

47. Ibid, paras [63] and [64].

48. [2002] EWHC 2278 (Admin), [2003] 1 FLR 292.

49. L Clements ‘Carers – the sympathy and services stereotype’ (2004) 32 British Journal of Learning Difficulties 6 at 7.

50. Section 3.

7. half-brother or half-sister;
8. friend of longstanding.⁵¹

Notably absent from this list is any reference to an individual who has played a role in informal caring for the deceased. The carer's relationship will have been indispensable to the deceased. The carer, who will have washed and cared for the body of the deceased for possibly years previously, will have no say in how it is treated after death. The bodies of the carer and cared for will have been interdependent during the care and this should be respected and reflected in giving the carer a voice in what happens to the deceased's body. True the carer may also be a spouse or partner or child and enter the list in that way, but this will not be by virtue of their caring role, but by virtue of the status of the relationship. Here again we see a failure to recognise or value the role of the carer.

Mental Capacity Act 2005

The Mental Capacity Act 2005 governs the treatment of people who lack mental capacity. An overriding principle of the Act is that when making decisions about a person who lacks capacity these decisions should be made on the basis of what is in the incompetent person's best interests. Section 4 provides some requirements for a person or court seeking to ascertain what is in a person's best interests. Of particular note, for the present purposes, is s 4(7):

'He must take into account, if it is practical and appropriate to consult them, the views of . . .

- (b) anyone engaged in caring for the person or interested in his welfare . . .
- as to what would be in the person's best interests . . .'

At first sight this may appear a welcome statutory acceptance of the importance of carers' views about what should happen to those they care for. However, it is important to note the restrictions on this. Most significantly, the carer may speak as to what would be in the incapacitated person's welfare. Their views as to what would assist them as carers is not a relevant consideration, unless it can be 'dressed' up as in the benefit of the individual. So, if the carer can say 'if my views on this issue are not listened to I will cease to care for the individual and hence it is in their interests that my views are accorded weight', then her views can be taken into account. But it would not be permissible to take into account the carer's views if she is saying that something would make her caring role much easier, if that could not be said to benefit the individual directly.

There are, of course, concerns that if weight is attached to a carer's views this could too easily lead to a position where decisions are taken that are harmful to the individual but are to the convenience of the carer. But, imagine a case where the primary carer must undertake a long and arduous journey to undertake her caring responsibilities each day. The possibility of moving the incompetent person much closer to the carer arises. Even though it might be possible to say (in a narrow sense) that the individual will not be benefited or harmed by the move, is it not justifiable to move the patient?

51. Section 27.

The case of *Re Y (Mental Patient: Bone Marrow Donation)*⁵² is instructive in how, in fact, the best interests test can be manipulated into taking account the interests of the incompetent person's family member. An application was made to remove bone marrow from Y, an incompetent woman, to give to her sister. Connell J authorised the operation stating that it could be said to be in Y's best interest. This was because the bone marrow was needed to save the life of the sister. If the sister were to die this would impact on the health of Y's mother and that would harm Y. The fact that Y's sister's life was in danger was therefore irrelevant except to the extent that her death might affect Y's welfare. Some have criticised the result in the case in that it involved using Y for another's benefit. However, I would suggest that the problem with the case is not the result but the reasoning. Surely it was of crucial importance that the bone marrow might save the sister's life. It would have been quite different if, say, the sister had required some skin for cosmetic surgery, even if such a 'donation' would have improved Y's relationship with her mother.⁵³ It seems the key question should have been whether in the family in which Y was part this donation was a reasonable aspect of the sacrifices made and benefits gained within the relationships. This is a controversial issue and one to which I will return later.

Mental Health Act 1983

The 'nearest relative' of a person detained under the Mental Health Act 1983 has a special place in the legislation to ensure the rights of detained people are respected. It is not appropriate to list here all the roles of the nearest relative under the legislative regime, but they include, for example, that the nearest relative must be consulted before an application is made to admit a patient under s 3. The definition of 'nearest relative' in s 26 is as follows:

1. husband or wife or civil partner;
2. son or daughter;
3. father or mother;
4. brother or sister;
5. grandparent;
6. grandchild;
7. uncle or aunt;
8. nephew or niece.

And if none of these are available under s 26(7), a person who has been residing with the patient for at least 5 years prior to the admission to hospital may be consulted. Carers, as carers, are not included at all. It is true that a person not included in the definition in s 26 could be appointed by the county court to act as the patient's nearest relative,⁵⁴ or be authorised to act as the nearest relative.⁵⁵

Notably, however, the legislation does take account of caring. Normally the nearest relative is the person highest up the list above. However under s 26(5) if the 'patient ordinarily resides with or is cared for by one or more his relatives' then that relative

52. [1997] 2 WLR 556.

53. I have discussed this case further in J Herring 'The welfare principle and parent's rights' in A Bainham, S Day Sclater and M Richards *What is a Parent?* (Oxford: Hart, 1999).

54. Mental Health Act 1983, s 29.

55. Mental Health (Hospital, Guardianship and Consent to Treatment) Regulations 1983, SI 1983/2156, reg 14.

will be the nearest relative unless there are others higher up the list who have undertaken a caring role or reside with the patient. It should be noted that this offers no status to a carer who is not also a relative. Further, it has no preference for a caring relative over a relative who resides with the patient, but does not provide care. Significantly, in the (now abandoned) Mental Health Bill 2004, specific obligations were imposed to consult with carers about the patient's wishes and feelings and to consider the impact of decisions on carers themselves.⁵⁶

LEGISLATION THAT DOES HELP CARERS

The government has announced that it takes the claims of carers seriously. The first significant milestone was the *National Carers Strategy*, published in 1999⁵⁷ Carers are assisted through the Carers (Recognition and Services) Act 1995, Carers and Disabled Children Act 2000 (the 2000 Act) and Carers (Equal Opportunities) Act 2004 (the 2004 Act).⁵⁸ These pieces of legislation are designed specifically to address the needs of carers. Most significantly, they give the carer who provides or intends to provide a substantial amount of care on a regular basis a right to receive an assessment for services for themselves as carers. This is separate from the assessment for the person cared for and therefore can be carried out even if the person cared for is not assessed.⁵⁹ The services to be provided can be anything that could 'help the carer care for the person cared for'. An assessment should include not just an assessment of the carer's physical needs, but also of their mental health and their attitude towards care. Department of Health guidance reminds local authorities that 'some people, for example, could provide care but may feel subject to a moral obligation to do so, or may feel defeated, trapped or depressed'.⁶⁰

The 2004 Act requires specific attention in such an assessment to be paid to a carer's wish for employment, learning or training opportunities and leisure.⁶¹ The 2000 Act extended rights of carers to include the right to support services, direct payments and vouchers. The 2004 Act also contains the practically important provision that social service departments have a duty to inform carers of their right to an assessment.⁶²

Luke Clements has written of the 2004 Act:

'The new Act marks a major cultural shift in the way carers are viewed: a shift in seeing carers not so much as unpaid providers of care services for disabled people, but as people in their own right: people with the right to work, like everyone else; people who have too often been socially excluded and (like the disabled people for whom they care) often denied the life chances that are available to other people.'⁶³

56. Clause 12(5).

57. Department of Health *Caring about Carers* (London: Department of Health, 1999).

58. Carers have limited rights to take (unpaid) time off work to care for a dependant. This right is found in Employment Rights Act 1996, s 57A(1).

59. Carers (Equal Opportunities) Act 2004, s 1.

60. Department of Health *Carers and Disabled Children Act 2000 and Carers (Equal Opportunities) Act 2004. Combined Policy Guidance* (London: Department of Health, 2005) para 43.

61. Carers (Equal Opportunities) Act 2004, s 2.

62. Section 1.

63. Clements, above n 8, para 1.4.

Although there is much to welcome in this legislation, there are a number of issues of concern surrounding it.

First, and most importantly, these provisions are largely permissive, authorising local authorities to provide these services if they wish, rather than dictating that they must. It is true that the existence of the statutory power may be of use in exerting pressure on local authorities to provide services, but are not likely to be an effective tool in pursuing legal remedies. That said, a blanket ban on providing services, or arbitrariness in the exercise of the power could be challenged in the courts.⁶⁴ Certainly, the Department of Health Practice Guidance encourages a radical shift in local authority practice in the provision of services to carers.⁶⁵ Further, £185 million has been given by the government for carers' grants, although the money is not 'ring-fenced' in 2005/06 (unlike previous years) and therefore there is no guarantee that it will be spent for that purpose.⁶⁶

It is difficult fully to assess the impact of the 2004 Act until more research has been carried out. In one survey, following an assessment only 37% of carers questioned saw an improvement in the services they were receiving.⁶⁷ No doubt the comments reported of one carer (Bernard) are far from atypical:⁶⁸ 'You get all these statements of intent to help, have these meetings, fill in dozens of multi-page forms, and then nothing happens. Except more talk, more forms, and endless waiting'.⁶⁹

As well as the issue about the provision of services for carers being mandatory, it is important to note that services offered to the carer can be charged for, subject to means testing.⁷⁰ This is in line with the controversial distinction between healthcare and social care for patients, the former being free, but the latter being liable to be charged for, subject to means testing. Carers UK opposed this move, arguing that many carers live in poverty and suffer financial hardship due to their caring role and to permit charging will only worsen their financial position.⁷¹ Their research has shown that the extra charges were causing serious financial hardship.⁷² Carers UK have also objected to inconsistency among the amounts charged by local authorities.⁷³ The fact that services for carers are means tested puts carers in a category similar to benefit claimants who are in need and must be provided for by the state; rather than recognising that they provide an invaluable service to society whose work requires recognition and reward, regardless of income.

A more significant challenge to the carers' legislation is an argument that carers and the cared for cannot be assessed separately. Inevitably, their interests are intermingled. An injury to the cared-for person will affect the carer; an injury to the carer will affect the cared-for person. The emotional well being of the carer will affect that

64. *R (on the application of Stephenson) v Stockton-on-Tees Borough Council* [2005] EWCA Civ 960, [2005] 3 FCR 248.

65. Department of Health *Carers and Disabled Children Act 2000. Practice Guidance* (London: The Stationery Office, 2001).

66. Carers UK *Policy Briefing: Carers Grant Guidance Year 7* (London: Carers UK, 2006).

67. Carers UK *Missed Opportunities: The Impact of New Rights For Carers* (London: Carers UK, 2005).

68. E Nicholas 'An outcomes focus in carers assessment and reviews: value challenge' (2003) 33 *British Journal of Social Work* 31.

69. H Marriott *The Selfish Pig's Guide to Caring* (Clifton-upon-Teme: Polperro, 2003) p 115.

70. Health and Social Services and Social Security Adjudications Act 1983, s 17.

71. Carers UK *Caring on the Breadline* (London: Carers UK, 2000).

72. *Ibid.*

73. *Ibid.*

of the cared-for person and vice versa. Therefore, to have independent assessments of the carer and the cared-for person is problematic.

Further, it is often difficult to know who is the carer and who is the cared for. This is most obvious in the very common case of elderly couples, where it may be that both their states of health are fluctuating and at different times each will be taking care of the other. But in another way the line between the carer and cared for is blurred. It is often only the gratitude and willingness of the 'cared for' to receive the care that enables the 'carer' to continue. The relationship is rarely all one way. Even in cases where the cared-for person is incapable of expressing anything in response to the care, care is still regarded as an aspect of the on-going relationship between the two people.

A HUMAN RIGHTS RESPONSE

A natural response to the issues surrounding carers, especially in the current climate, is to focus on claims for legal rights.⁷⁴ In the context of carers, a number of human rights claims could be made:

1. The right to protection from discrimination. An argument could be made that carers should not be discriminated against because of their carer status. Hence it has been argued that just as disabled workers have rights requiring their employers to make reasonable provision for their disability, a similar obligation should be imposed on employers in respect of carers. Luke Clements writes:

'Carers should have the same life chances as anyone else. The mere fact they are providing care should not disentitle them to opportunities available to people who do not have caring responsibilities. To argue otherwise would be to suggest that it is legitimate to discriminate against carers in a way that would not be acceptable for any other group. If it is unacceptable to assert that disabled people should not expect to work or participate in education or expect to have meaningful personal relationships, then how could one possibly suggest that this is not also the case for carers?'⁷⁵

Putting the argument in terms of the European Convention for the Protection of Human Rights and Fundamental Freedoms 1950 (ECHR) reference could be made to Art 14, which states that the rights protected by the ECHR 'shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status'. Of course carers as a group do not fall directly into one of the categories mentioned in Art 14. Nevertheless, as the European Court of Human Rights has pointed out, the words 'such as' indicates that this is not a closed list.⁷⁶ However, it may be argued that being a carer is unlike race or sex, for example, because it is a role one chooses to adopt and is not an 'immutable' characteristic.⁷⁷

74. I am grateful to Rachel Taylor for some helpful advice on this section.

75. Clements, above n 8, para 4.40.

76. *Da Silva Mouta v Portugal* [2001] 1 FCR 653.

77. In *R (on the application of Hooper) v Secretary of State for Work and Pensions* [2005] UKHL 29, [2005] 1 WLR 1618, Lord Hoffmann (at para [65]) suggested that to fall within Art 14 the characteristic had to be at least analogous to those mentioned in Art 14. See S Fredman *Discrimination Law* (Oxford: Oxford University Press, 2002) p 79 for a powerful argument against requiring immutability for a ground of discrimination.

Further, it might be argued that carers as a category of people lack a group identity, of the kind required for recognition for protection. However, it is doubtful whether ‘immutability’ or ‘group identity’ are required for a ground of discrimination. Illegitimacy and marital status do not fall into both of these headings and yet are accepted as grounds of discrimination. As Sandra Fredman, rejecting the view that immutability is a requirement for a ground of discrimination, argues that ‘a person or group has been discriminated against when a legislative distinction makes them feel that they are less worthy of recognition or value as human beings, as members of society’.⁷⁸ As has been argued above, this description appears apt for informal carers in our society.⁷⁹

Article 14 is not, of course, a free-standing Article. In other words, a carer would not be able to claim in the abstract that she was suffering discrimination. Rather, it would be necessary for her to demonstrate that one of the rights protected by the ECHR was interfered with in a way which was discriminatory, contrary to Art 14. The most obvious claim would be that a carer’s right to respect for her private or family life was interfered with in a way which was discriminatory on the grounds of her caring status. We shall discuss this right next.

2. The right to respect for private and family life. A carer can claim that their relationship with the cared-for person is protected by Art 8 of the ECHR. If the cared-for person and carer are relatives then there will be no difficulty in arguing that their relationship falls within the category of family. But if they are not blood relatives, there is an argument that they can still be regarded as having family life. The European Court of Human Rights has accepted that foster carers and the children they look after can have family life.⁸⁰ Even if a claim to family life fails, a strong case can be made for their relationship to be protected by the right to respect private life under Art 8.⁸¹ This part of Art 8 has been said to include the right to ‘establish and develop personal relationships’.⁸²

Article 8 contains both positive and negative aspects. In negative terms, the state must not interfere in an individual’s private and family life unless to do so is necessary under the terms of Art 8(2) – for example it is necessary to protect the interests of others. This would provide some protection in the case of incapacitated adults being removed from their carers without clear proof of significant harm.

More significant is the positive obligation under Art 8.⁸³ This requires that the state, on occasion, provide services or otherwise act in a way to enable a person to maintain a family relationship. This is, of course, limited. A state is only required to take reasonable steps. A strong case can be made for there being a right to assistance where the alternative is the separation of the carer and the cared-for person.

78. Ibid, p 82.

79. Although in *R (on the application of Hooper) v Secretary of State for Work and Pensions* [2005] UKHL 29, above n 77 and *R (on the application of Carson) v Secretary of State for Work and Pensions* [2005] UKHL 3337, [2005] 2 WLR 1369 the House of Lords has been strict in its interpretation of Art 14.

80. *Rieme v Sweden* (1992) 16 EHRR 155; *Cyprus v Turkey* (1976) 4 EHRR 282.

81. *Znamenskaya v Russia* [2005] 2 FCR 406: ‘it has also been the Convention organs’ traditional approach to accept that close relationships short of “family life” would generally fall within the scope of “private life”’ (para [27]).

82. *Pretty v UK* (2002) 35 EHRR 1 para 61.

83. A Mowbray *The Development of Positive Obligations under the European Convention on Human Rights by the European Court of Human Rights* (Oxford: Hart, 2003).

3. The right to protection from torture or inhuman or degrading treatment is protected by Art 3 of the ECHR. This Article also imposes positive and negative obligations on the state. Not only must the state not torture or inflict inhuman or degrading treatment on its citizens, it must protect citizens from torture or inhuman or degrading treatment at the hands of other people, insofar as it is reasonable.⁸⁴ Hence, if the state is aware that children are suffering abuse and fails to offer them protection, the state is said to thereby infringe the children's rights under Art 3.⁸⁵ Of course, not all carers will be able to describe their position as amounting to torture or inhuman treatment, but certainly quite a few carers may be able to claim that their standard of life has reached such a level. Further, although the obligation to protect children and other vulnerable people from inhuman or degrading treatment is established, it is not clear that the courts would be as willing to find an obligation on the state where the individual is competent.

From a broader perspective, in Martha Fineman's *The Autonomy Myth*⁸⁶ the claim is made that as carers provide much benefit to society there is a debt owed to them by society. She explains:

'The theory of dependency I set forth develops a claim of "right" or entitlement to support and accommodation from the state and its institutions on the part of caretakers – those who care for dependents. Their labor should be treated as equally productive even if unwaged, and should be measured by its societal value, not by economic or market indicators. The fact that dependency work has been un- or undervalued in the market is an argument *for* governmental intervention and restructuring to mandate adjustment and market accommodation, as well as more direct reparations.'⁸⁷

She therefore argues that:

'Caretaking thus creates a "social debt", a debt that must be paid according to principles of equality that demand that those receiving social benefits also share the costs when they are able. Far from exemplifying equal responsibility for dependency, however, our market institutions are "free-riders", appropriating the labor of the caretaker for their purposes.'⁸⁸

It is not possible here to analyse in depth the sophisticated argument which she develops. There are, however, some dangers with it. One might argue that if society is liable to 'pay' for care, it might feel a greater entitlement to police the standard of care and to consider whether there are economically more efficient ways of providing care.⁸⁹

THE ETHIC OF CARE

As we have seen in all too many areas, carers are barely acknowledged. Medical law and ethics have been obsessed with an individualised notion of rights for too long.

84. *E v UK* [2002] FCR 700.

85. *Ibid.*

86. M Fineman *The Autonomy Myth* (New York: New Press, 2004).

87. *Ibid.*, p xv.

88. *Ibid.*, xvii.

89. M Eichner 'Dependency and the liberal polity: on Martha Fineman's *The Autonomy Myth*' (2005) 93 *California Law Review* 1285.

Perhaps understandably, the impetus behind medical law has been to empower patients against the authority of medicine and its professionals. There was nowhere for medical law or ethics to go until there was a serious challenge to medical paternalism. The focus on the rights of autonomy and bodily integrity was essential if there was to be a challenge to the supremacy of the professional medical opinion. But the focus on these rights too readily created a legal image of an isolated individual patient.

The invisibility of carers in the law has more to it than that. Caring is a gendered activity. It is seen as 'women's work' and as such is ignored in the 'male gaze'. I mentioned earlier the enormous economic value of care and yet it is not given the respect or recognition that other higher profile 'economically productive' activities have. By describing care work as 'voluntary' and 'informal' it is marginalised as unimportant. Hence, the professional doctor-patient relationship is subject to careful and extensive legal regulation and is dealt with at length in the court reports and the wider media. The carer-patient relationship, of greater significance to many patients, is ignored.⁹⁰ This all has the impact of care work being unvalued and unnoticed. All of this is convenient to a society in which 'men's' work goes rewarded and valorised, while 'women's' work is invisible and unrecognised. The lack of respect owed to caring has played a significant role in the unequal economic position of women.⁹¹

The legal image of the isolated patient whose rights need protection is a fiction. Here, as often in legal writing, the law presumes an autonomous competent man who can enforce his rights. The reality is that we are ignorant, vulnerable, interdependent individuals, whose strength and reality is not in our autonomy, but our relationships with others.⁹²

Many of those rejecting the individualised vision of rights have turned to ethics of care as an alternative.⁹³ The ethic of care has been particularly developed and found support among feminist thinkers. It promotes a vision of us with mutually interdependent relationships as the norm around which legal and ethical responses should be built. Carol Gilligan explains, 'The ideal of care is thus an activity of relationships, of seeing and responding to need, taking care of the world by sustaining the web of connection so that no one is left alone'.⁹⁴

Our visions of ourselves must be fluid: we cannot easily break down into 'me' and 'you' when in a relationship. To harm a child is to harm her carer; to harm the carer is to harm the child. To claim, as some judges shockingly have done, that a father can be violent towards his child's mother, but be committed to the child, is to separate individuals inappropriately.⁹⁵ The values that are promoted within an ethic of care are

90. J Finch and D Groves 'Community care and the family' (1980) 9 *Journal of Social Policy* 287.

91. C Ungerson 'Thinking about the production and consumption of long-term care in Britain: does gender still matter?' (2000) 29 *Journal of Social Policy* 623.

92. C Meyer 'Cruel choices: autonomy and critical care decision-making' (2004) 18 *Bioethics* 104.

93. Eg C Gilligan 'Moral orientation and moral development' in E Kittay and D Meyers (eds) *Women and Moral Theory* (Totowa: Rowman and Littlefield, 1987); M Friedman, *Liberating Care* (Ithaca: Cornell University Press, 1993); S Sevenhuijsen *Citizenship and the Ethics of Care* (London: Routledge, 1998); R Groenhout *Connected Lives: Human Nature and an Ethics of Care* (Totowa: Rowman and Littlefield, 2004); V Held *The Ethics of Care* (Oxford: Oxford University Press, 2006).

94. C Gilligan *In a Different Voice: Psychological Theory and Women's Development* (Cambridge MA: Harvard University Press, 1984) p 73.

95. *Re JS* [2002] 3 FCR 433.

not isolated autonomy or the pursuance of individualised rights, but rather those of promoting caring, mutuality and interdependence.

Here are the key aspects of the ethic of care as they relate specifically to carers:

1. The inevitability of interdependence, not self-sufficiency

Care is an inevitable part of life.⁹⁶ At the very start of life, we are in a relationship of dependency, and often we are just as dependent at the end of life. Care is a daily reality for most people. It is true that during the course of life the balance between caring and being cared for may shift. But, caring is the very essence of life.⁹⁷ It is part of being human. Without it, society would soon collapse. The law must regard relationships as key to its thinking and not ignore them.

2. The value of care

Care ethicists would argue that not only is care an inevitable part of life, but that it is a good part of life. As Robin West puts it:

‘Caregiving labor (and its fruits) is the central adventure of a lifetime; it is what gives life its point, provides it with meaning, and returns to those who give it some measure of security and emotional sustenance. For even more of us, whether or not we like it and regardless of how we regard it, caregiving labor, for children and the aged, is the work we will do that creates the relationships, families, and communities within which our lives are made pleasurable and connected to something larger than ourselves.’⁹⁸

Caring, then, is a ‘major life activity’⁹⁹ that benefits not just the person receiving the care, but also the person giving the care, and society more widely.¹⁰⁰

From a feminist perspective there is a danger in seeking to have care valued. The danger is that they might be seen as justifying or encouraging women to undertake unpaid care work. However, care ethics seek to ensure that value is attached to care so that those who undertake ‘love labour’¹⁰¹ are not disadvantaged. If society were to attach importance and value to care it might become an activity in which both men and women would seek to partake equally.¹⁰²

96. Fineman, above n 86, p xvii.

97. F Williams ‘The presence of feminism in the future of welfare’ (2002) 31 *Economy and Society* 502.

98. R West ‘The right to care’ in E Kittay and E Feder (eds) *The Subject of Care: Feminist Perspectives on Dependency* (Lanham: Rowman and Littlefield, 2002) p 89.

99. A Hubbard ‘The myth of independence and the major life activity of caring’ [2004] 8 *Journal of Gender, Race and Justice* 327.

100. L. McClain ‘Care as a public value: linking responsibility, resources, and republicanism’ [2001] 76 *Chicago-Kent Law Review* 1673; M Daly ‘Care as a good for social policy’ [2002] 31 *Journal of Social Policy* 251.

101. See K Silbaugh ‘Turning labor into love: housework and the law’ [1996] 91 *Northwestern University Law Review* 1.

102. J Williams ‘From difference to dominance to domesticity; care as work, gender as tradition’ [2001] 76 *Chicago-Kent Law Review* 1441. There would also need to be changes in the employment market to ensure that employed work was a realistic and attractive option for women: T Knijn and C Ungerson ‘Introduction: care work and gender in welfare regimes’ [1997] 32 *Social Politics* 323.

3. The relational approach of ethics of care

One of the most attractive aspects of an ethic of care approach is that it seeks to move away from an atomistic picture of individuals, with rights that compete against each other, to a model that emphasises the responsibilities of people towards each other in mutually supporting relations.¹⁰³ So rather than the focus of the inquiry being whether it is my right to do X, the question is what is my proper obligation within the context of this relationship.¹⁰⁴ Virginia Held makes the point by contrasting ethics of care and an ethic of justice:

‘An ethic of justice focuses on questions of fairness, equality, individual rights, abstract principles, and the consistent application of them. An ethic of care focuses on attentiveness, trust, responsiveness to need, narrative nuance, and cultivating caring relations. Whereas an ethic of justice seeks a fair solution between competing individual interests and rights, an ethic of care sees the interest of carers and cared-for as importantly intertwined rather than as simply competing.’¹⁰⁵

It should be added that Held makes it clear that an ethic of care includes justice:

‘There can be care without justice. There has historically been little justice in the family, but care and life have gone on without it. There can be no justice without care, however, for without care no child would survive and there would be no persons to respect.’¹⁰⁶

There is another important aspect of this issue. That is that emphasising interdependence and mutuality means that the division between carer and cared for dissolves. As Michael Fine and Caroline Glendinning argue:

‘Recent studies of care suggest that qualities of reciprocal dependence underlie much of what is termed “care”. Rather than being a unidirectional activity in which an active care-giver does something to a passive and dependent recipient, these accounts suggest that care is best understood as the product or outcome of the relationship between two or more people.’¹⁰⁷

In truth there is often give and take in the ‘carer’ and ‘cared-for’ relationship. Their relationship is marked by interdependency.¹⁰⁸ The ‘cared for’ provides the ‘carer’ with gratitude, love, acknowledgement and emotional support. Indeed, often a ‘carer’ will be ‘cared for’ in another relationship. As Diane Gibson has argued, our society is increasingly made up of overlapping networks of dependency.¹⁰⁹

Clare Ungerson has convincingly argued that it is wrong to see the relationship between ‘carer’ and ‘cared for’ as one where the ‘carer’ has power over the ‘cared

103. G Clement *Care, Autonomy and Justice: Feminism and the Ethic of Care* (New York: Westview, 1996) p 11.

104. Held, above n 94, p 1.

105. Ibid, p 15.

106. Ibid, p 17.

107. M Fine and C Glendinning ‘Dependence, independence or inter-dependence? Revisiting the concepts of care and dependency’ (2005) 25 *Ageing and Society* 601 at 619.

108. T Shakespeare *Help* (Birmingham: Venture, 2000) and T Shakespeare ‘The social relations of care’ in G Lewis, S Gewirtz and J Clarke (eds) *Rethinking Social Policy* (London: Sage, 2001).

109. D Gibson *Aged Care: Old Policies, New Solutions* (Melbourne: Cambridge University Press, 2005).

for'.¹¹⁰ The 'cared for' might have a range of powers they can exercise. The emotional well being of the carer can depend on the attitude and response of the 'cared-for' person to the carer. The 'cared for' has the power to make the life of the carer unbearable.

CRITICS OF AN ETHIC OF CARE

Of course, the concept of an ethic of care is not without its critics. Emily Jackson has recently described the ethic of care as 'an inherently vague concept, which could be used to justify almost any plausible moral argument'.¹¹¹ She points out that in relation to euthanasia, ethics of care could be used to support or oppose euthanasia. This is, with respect, a rather unfair criticism. Exactly the same thing could be said about the concept of human rights. Indeed, one should be highly sceptical of any broad ethical approach that provides a single answer to a complex issue such as euthanasia. An ethic of care, like the concept of rights, provides ethical tools with which to analyse a situation, but it does not provide the answer. The fact that it can be used to support and oppose euthanasia should be seen as a strength, not a weakness, of the concept.

Jackson's argument that the notion of care itself, which is at the heart of the approach, is vague has more merit. This, however, is to overlook the extensive work that ethics of care theorists have done to give greater clarity to the concept of care.¹¹² Even if it does still lack precision, this is equally true of concepts such as the right to dignity, justice or privacy, which are widely respected and used by lawyers and ethicists.

Another common criticism of an ethic of care relates to a rather unfortunate aspect of its history.¹¹³ Ethic of care rose to prominence with the writing of Carol Gilligan¹¹⁴ who sought to distinguish between a 'male' approach to ethical issues, which focused on concepts of justice; and a 'female' approach to ethical issues, which focused on concepts of care. While undoubtedly the 'grandmother' of care ethics (and who would want to speak ill of their grandmother), the 'second generation'¹¹⁵ of care ethicists has tended to downplay the argument that the ethic of care is a female way of thought.¹¹⁶ Further, the sharp divide between justice and care is not normally relied upon nowadays. An ethic of care wishes to promote relationships, but only those relationships which are just. As Robin West puts it:

110. C Ungerson 'Social politics and the commodification of care' [1997] 4 *Social Policy* 362.

111. Jackson, above n 1, p 22.

112. Eg Held, above n 93; D Koehn *An Ethic of Care* (London: Routledge, 1998).

113. Jackson, above n 1, p 22 suggests that ethics of care has nothing to say about social policy. This is simply untrue: see, eg, O Hankivsky *Social Policy and the Ethic of Care* (Vancouver: University of British Columbia Press, 2005).

114. C Gilligan *In a Different Voice: Psychological Theory and Women's Development* (Cambridge MA: Harvard University Press, 1982) pp 1–4 and 24–63.

115. Hankivsky, above n 113, p 2.

116. Repeats of the experiments used by Carol Gilligan in European countries have not found the differing responses to ethical issues tied to sex in the way she did: A Vikan, C Camino and A Biaggio 'Note on a cross-cultural test of Gilligan's ethic of care' (2005) 34 *Journal of Moral Education* 107.

‘Relationships of care, untempered by the demands of justice, resulting in the creation of injured, harmed, exhausted, compromised, and self-loathing “giving selves”, rather than in genuinely compassionate and giving individuals, are ubiquitous in this society.’¹¹⁷

So arguments that an ethic of care perpetuates assumptions that women are naturally drawn to caring roles,¹¹⁸ or that it overlooks the potential for abuse within relationships, are usually based on a rather old-fashioned (mis)understanding of what the ethic of care is about.

PUTTING AN ETHIC OF CARE INTO PRACTICE

Under an ethic of care the practice of caring would be hugely valued within society. Carers would, far from being hidden, come to represent a norm. Social structures and attitudes would need to be set up to encourage and enable caring. This would require adequate remuneration of carers: not the payment of benefits of the kind paid to those ‘unable to work’, but payment acknowledging the key role they play.¹¹⁹ Work would need to be done to ensure that the burden of caring did not fall on the few but was shared across the community.

When assessing the rights of any individual or the medical needs of an individual, such a person would have to be considered in a situational context. Never should it be a matter of assessing person X in isolation. Rather each person’s needs and rights would have to be considered in the context of their relationships. For example, in the social work literature on carers, there is much debate over whether respite care should be regarded as a service for the carer or cared-for person.¹²⁰ Of course the reality is it is a service for both people. The carers’ legislation in promoting the separate assessments of both carer and cared for creates an artificial and inappropriate divide. The better approach is to assess and provide those services which will promote the caring relationship.

Earlier reference was made to the Mental Capacity Act 2005 and the fact that although carers’ views about what would be in the best interests of the patient can be taken into account, the decision can only be made based on what is in the best interests of the patient, and the interests of the carers are not mentioned. It is argued that this is misguided. It is not possible to consider the incompetent person without considering the well being of the incompetent person’s carer. The interests of the two are intertwined. No carer could possibly undertake the task of caring if every decision which has to be made was solely on the basis of what is in the interests of the cared-for person. No one would want to be cared for in a relationship in which the carer’s interests counted for nothing. The relationship of caring does, and should, involve give and take. It would not be in the interests of a cared-for person to be in a relationship which was utterly oppressive of their carer. What *is* in their interests is to be in a relationship with their carer which promotes the interests and well being

117. R West *Caring for Justice* (New York: New York University Press, 1997) p 81.

118. Jackson, above n 1, at 22.

119. The payment of carers has been said to carry dangers of causing the ‘marketisation of intimacy and the commodification of care’; C Ungerson ‘Cash in care’ in M Harrington Meyer (ed) *Care Work: Gender Class and the Welfare State* (London: Routledge, 2000) p 69.

120. B Gillies ‘Acting up: ambiguity and the legal recognition of carers’ (2000) 20 *Ageing and Society* 429.

of both of them.¹²¹ It is, therefore, argued that when considering the best interests of an incompetent person, such an assessment must consider their well being in the context of their relationships. This might involve making decisions which in a narrow way do not explicitly promote the incompetent person's welfare or even slightly harms it, if that is a fair aspect of a caring relationship which is a necessary part of the incompetent person's well being.

An important aspect of the ethic of care, but one that is often overlooked by care ethicists, is that part of valuing and promoting caring relationships is the protection of people who are rendered vulnerable in caring relationships. We need to promote 'just care'.¹²² There is a danger that an ethic of care can valorise care.¹²³ We know that under the label of care disturbing levels of abuse of vulnerable adults has occurred. It is essential that the ethic of care promotes only those relationships that do not lead to the mistreatment of either party. There is a tension in ethics of care thinking which, while focussing on the relationship, must not lose all sight of the impact of that relationship on the individuals within it.

So, what about Michael, the man refusing to consent to a hip replacement, I posited at the start of this paper? Could it ever be appropriate to claim that the interests of his carer would justify forcing the operation upon him? Because if not, and if the 'right of autonomy of the patient' always trumps the interests of carers, it might be asked whether, in reality, there is much point in seeking to emphasise the interests of carers.

In an extreme case, I think it would be appropriate for Michael to be required to undergo the operation. If the burden of caring for Michael without the replacement hip would place on the carer an enormous burden (eg it would pose serious risks to the carer's health) and where Michael wishes that caring relationship to continue, then it may be part of his responsibility to undergo the operation.¹²⁴ Indeed, it may be far from straightforward what Michael wants in this scenario. He has said that he does not want the operation, but presumably he wants the caring relationship to continue. No doubt he does not want to place oppressive burdens on his carer. The difficulty for him is that the law cannot meet these conflicting wishes. If this is a relationship of long standing which is one that the law should respect (eg there has been no abuse) then the law must reach the decision that encourages and enables that relationship to continue. If that requires the operation, so be it. And, in any event, as indicated, it is not obvious that it would be infringing rights to autonomy if, when considering what Michael wants in this situation, we consider the full range of his conflicting wishes.

CONCLUSION

A few months ago the Commission for Social Care Inspection had this to say about the position of carers:

121. For a development of this approach in relation to parents and children, see J Herring 'The Human Rights Act and the welfare principle in family law – conflicting or complementary?' [1999] CFLQ 223.

122. C Koggel 'Care and justice; re-examined and revised' [1999] Paideia 24 December.

123. B Hughes et al 'Love labour's lost?' (2005) 39 Sociology 259.

124. For an excellent discussion on the importance of responsibilities in medical law and ethics, see M Brazier 'Do no harm – do patients have responsibilities too?' [2006] Cambridge Law Journal 397.

'Over time, the day in, day out pressures on family carers were seen to wear people down. Coping with a mix of physical and mental problems was said by carers to be particularly burdensome. Despite the higher profile of carers' needs, and improvements in the number of separate assessments being done, this study found an excessive strain on some family members, especially partners who were themselves elderly and frail. In practical terms, there appeared to be still too few services available in some places specifically to respond with speed and flexibility to carers' assessed needs and professionals still tended to be relying excessively on the commitment of carers.'¹²⁵

The activities of carers are undervalued in our society and the caring is done by some of the most powerless people within our society.¹²⁶ Notably, women are disproportionately involved in caring.¹²⁷ There is a serious lack of resources for those caring for others.¹²⁸ As Clements points out, 'the solution and social exclusion many carers experience are not inevitable or necessary consequences of caring, but social manifestations of a disabling environment'.¹²⁹

Few would disagree. What is less straightforward is the way to proceed. As already discussed, the 'natural' response for lawyers is to call for a rights-based approach seeking a variety of ways of promoting the human rights of carers and to emphasise the economic benefits provided by carers. However this, it is suggested, is inimical to the notion of caring itself. To see cases of caring as involving the rights of the carer, the person cared for and the others with relevant interests clashing against each other and having to be weighed against the wider social good is to overlook the true nature of caring, which involves relationship, mutuality and interconnection.

The government policy towards older and disabled people can appear confused. We have already seen the government's claims to take the role of carers seriously. Yet, at the same time, the government has emphasised the importance of older people being independent. For example, the government in March 2006 introduced a raft of measures to enable older people to be given the choice of living at home.¹³⁰ The Audit Commission produced an important paper entitled *Older People: Independence and Well-being*,¹³¹ which accepted that care is essential to enable independence.

This paper has advocated an approach based on an ethic of care. Such an approach recognises that relationships of dependency within 'caring relationships', far from being problematic, are in fact the 'norm'. The approach to such cases should not isolate the individual interests of the parties and seek to analyse them separately, as the Carers (Equal Opportunities) Act 2004 does with its individual assessments for carers and the cared for. Instead, we should promote ways of supporting and upholding the caring relationships. Further, there should not be a sharp

125. Commission for Social Care Inspection *Leaving Hospital Revisited* (London: Commission for Social Care Inspection, 2005).

126. J Toronto *Moral Boundaries* (London: Routledge, 1993) p 113.

127. D Bubeck *Care, Gender and Justice* (Oxford: Clarendon Press, 1995).

128. J Read 'Will the Carers and Disabled Children Act 2000 make a difference to the lives of disabled children and their carers?' (2002) 28 *Child Care, Health and Development* 273.

129. Clements, above n 49.

130. Department of Health *More Older People to be given Choice to Live at Home* (London: Department of Health, 2006).

131. The Audit Commission *Older People: Independence and Wellbeing* (London: The Audit Commission, 2004) para 94.

divide between the person who is being cared for and who the carer is.¹³² Rarely is it that simple.

This is not to idealise caring. In his book, *The Selfish Pig's Guide to Caring*, Hugh Marriott, clearly a devoted carer himself, has this to say:

'We didn't apply for the job. Most of us don't have a vocation for it. We've had no training. We're certain we aren't much good at it. Plus, and this is the nub of the matter, we've got our own life to lead. Are we expected to throw that away because of somebody else's disability? We've got things to do, places to go. And now it looks as if we might not be able to.

But aren't we just as important as they are? Why are we expected to sacrifice ourselves for somebody else? And yes, I mean sacrifice. We're not talking about giving up five minutes of time once or twice a week. Or putting off a holiday from this year to next. We're talking about changing our entire way of life. The old one wasn't perfect, but it was the best we could do. This new one isn't even ours. It's somebody else's life. And it's one that doesn't suit us at all.'¹³³

This is no glamorised self-less caring, but the mucky, nasty, frustrating caring of real life.¹³⁴ Care is hard work; extremely hard work.¹³⁵ Carers can often feel trapped: their life goals come to an end and they must adopt the role of carer while the rest of their life is put on hold.¹³⁶ But it is caring that is the heart of life.

We are not self-sufficient but interdependent; not isolated individuals but people in relationship; not people with rights clashing with those who care for us and for whom we care, but people who live with entwined obligations and interests with those we love. We are not easily divided up into carers and cared for. We are in mutually supportive relationships. We need then a legal and ethical approach that promotes just caring: respects it; rewards it; and protects those rendered vulnerable by the caring role – an approach which has relationship at its heart. After all care is about love. And love is not about 'you' and 'I'; it is about 'us'.

132. E Nicholas 'An outcomes focus in carers assessment and review' (2003) 33 *British Journal of Social Work* 31.

133. Marriott, above n 69, p 9.

134. K Abrams 'The second coming of care' (2001) 76 *Chicago-Kent Law Review* 1605; J Oliver and A Briggs *Caring Experiences of Looking after Disabled Relatives* (London: Routledge, 1985).

135. Hubbard, above n 99; Ungerson, above n 110.

136. Department of Health, above n 57, para 69.