A Death of One's Own

MARTIN HOLLIS

> The wish to have a death of one's own is growing ever rarer. Only a while yet and it will be just as rare to have a death of one's own as it is already to have a life of one's own.
>
> Rainer Maria Rilke

Rilke's remark conjures up an officious array of well-meaning persons bent on completing our orderly passage from cradle to grave. They tidy our files cosily about us, inject us with extreme unction and slide us into the warm embrace of the undertaker. At the forefront of the array stands the doctor, part mechanic and part priest. His main task is to repair the living with resources whose effective and impartial allocation is a chief topic of medical ethics. But his role is not that of an impartial allocator: his patients want his partisan support. This builds a moral tension into a role played out where system meets patient, and one made instructively plain in the care of the dying. The system no doubt prefers death to be cheap and orderly but this thought may not move someone like Rilke wanting a death of his own. The doctor is then caught between his general duty to patients at large and his particular duty to the patient in front of him, a tension tautened for a Hippocratic promoter of health and life by a patient in search of an exit.

To put flesh on the theme, let us start with an awkward case for the doctor. George is an old man, a widower, in hospital after a stroke. Although fairly well recovered, he is still fragile and has poor balance. But he is clear-headed, especially about his wish to go home. He says firmly that he could manage on his own; and so he probably could, if he had enough support. Otherwise there is a real danger of his falling, fracturing a leg and being unable to summon help. There is a risk of hypothermia. He may easily become dirty, unkempt, emaciated and dehydrated, since it is not plain that he can dress, toilet and feed himself for long. He may not manage to comply with his medication. He might perhaps even become a risk to others by leaving his fire unattended or causing a gas explosion. None of this would be worrying, if there was a supporting cast. But his house is not suited to his condition. His only relative is his daughter, living elsewhere, with her own job and family and not willing to take George on. His neighbours are unfriendly. Social Services can offer something—perhaps a home help, meals on wheels, a laundry service, day care, an alarm service. But this does not truly cover nights and weekends and, anyway, George is liable not to

eat the meals and not to accept the day care. Meanwhile the advice from social services is that he should stay in hospital. It is good advice for the further reason that there will be no second chance. Often one can allow a patient a try at looking after himself, knowing that he can be scooped up and returned to hospital, if necessary. But George is too fragile and too alone for this to be a promising option. Yet he is in no doubt that he wants to go home and denies that he needs any of the missing support.

This situation was described to me by an experienced GP as one commonly encountered and ethically difficult.[1] He added two questions. How much self-determination should George be allowed, given that his insight is poor? How much responsibility does the doctor shoulder, if he colludes with George's wishes? Both questions sound easy, if one begins by disputing their assumption that they can be posed primarily from the doctor's point of view. Or so I supposed, until I tried the familiar philosophical tactic of challenging the assumptions and found that the still waters run awkwardly deep. In what follows, I shall open with George's point of view and try to extract a line which gives the doctor clear guidance. Having duly failed, I shall then address the tension between system and patient as claimants on the doctor's integrity, before finally reverting to George's own wishes for his life or death.

The first question was how much self-determination George should be allowed, given that his insight is poor. As a preliminary, the story, as told, does not guarantee that George's insight is poor at all. It could be that he has a pretty shrewd idea that he will not last long on his own but simply wants to go home to die. Being also shrewd enough to know that he cannot expect the doctor's co-operation on those terms, he takes on the conventional patient's role in a well-tried dramatic dialogue between confident patient and concerned doctor. It is both polite and politic to offer the doctor clean hands by persuading him that the patient has the determination to cope. It is both polite and politic for the doctor to collude in what is, after all, not exactly the doctor's business, once he has been offered enough to satisfy any later enquiry into negligence. Under the surface of the conventional dialogue another has been conducted. George's questions about his true condition, asked and unasked, have been answered and advice given. George has rejected the advice, absolving the doctor of private and public responsibility. Honour has been satisfied on both sides.

I raise this possibility as a way of ushering one what one might call a decent liberalism. Traditionally the doctor's role is attended with more

[1] I would like to thank Dr Brian Cole warmly both for this starting point and for help in seeing what might be done with it philosophically. I am also grateful to Albert Weale for comments on an earlier draft.

paternalism than a liberal doctor may relish. The liberal reminds us that today's doctor is no longer God and should not play God. He is the patient's servant, not his master. If George really did want to live out a full, self-sufficient life and was suffering from illusions, brought on perhaps by resentment at the humiliations of hospital routine, then the doctor might have a duty to be obstructive. But a good servant accepts his master's wishes and, in so far as George is weary of the world, the doctor is not his judge. Doubts about George'a autonomy, a liberal would say, should be resolved in George's favour and a discreet way found of avoiding scandal. George's insight is not *outrageously* poor and there is a chance that it is not poor at all.

The crux for this liberal line does not depend on whether the doctor has a formal power to keep George in hospital or is merely giving authoritative advice which he can make prevail. Whichever kind of authority it is, he should use it to uphold George's genuine wishes. This directive applies broadly even where George is under some illusion about his likely power to cope but is not exactly brimming with the will to live. The doctor's moral responsibility is to be supportive when he can, and *in loco parentis* only when he must.

We can distinguish two routes to this result. One starts by thinking of patients as bodies and of doctors as mechanics. George has, so to speak, brought his rickety old Ford to the garage with a big end gone and been told, that, although pretty clapped out, it would do a few thousand more miles, if left in for further repairs. Some garages are gleaming hi-tech affairs, which strip the car down in a flash and will not give it back until the bemused owner has signed an open cheque for whatever the garage sees fit to do. The medical equivalent of these motoring pits are hospital wards ruled by lordly consultants with acolytes, who strip away the patient's identity and turn him into an object before pretending to consult him on the technology of his health. But there are liberal garages too. There the owner is given an assessment before the dismantling starts and, even if nudged with a spot of advice, is left to make the decision. What makes this traditionally liberal is less its general view that, as J. S. Mill put it, there is a circle round each individual human being, which it is not the job of government or anyone else to invade, and more its particular presumption (also to be found in Mill) that a person is a mind, who owns a physical machine whose disposal is up to the owner.

The liberal line becomes trickier, if, as has become fashionable of late, one reverts to the ancient view that patients are not bodies but *persons,* and adds that a person is not a mind lodged in a body like a pilot in a vessel or motorist in a car. This subverts the idea that the doctor is just a mechanic and hence subverts one neat way of denying that the doctor is God. The other liberal route to granting the patient's auto-

nomy thus starts from an idea of respect for *persons*. For all its greater current plausibility, it is stonier, however, and I am not sure that it gets there. Here are some of the complications.

George's chances of coping on his own seemed at first to depend merely on the support available for his rickety physical machine. But, if George is thought of as a *person,* we shall have to notice that psychological and social factors matter too. To discuss the social factors would take me too far afield. So let me just say that George's chances of recovering manageably from a stroke may vary with his class, gender, income and previous occupation, and that strokes may belong in a mysterious category, along with, for example, cot deaths and schizophrenia, where it looks as if social factors may even be causal. Meanwhile there is the obvious social point that he would get on better if he had friendly neighbours. In brief, the likely health of *persons* cannot be assessed in social isolation.

More directly relevant are the psychological factors. George's chances depend on his state of mind—his desires, beliefs and strength of will—which the doctor who treats George as a person must take into account. An instant complication is that the doctor's diagnosis or prognosis can affect George's chances. For an extreme case reflect on the common tale that in cultures which believe in witchcraft the knowledge that he has been cursed is enough to make a man curl up and die. In George's case there is an obvious risk that, in establishing his chances of survival, the doctor will upset his precarious balance and thus improve his insight at the expense of his health. In general the liberal view is that knowledge is always a Good Thing and, in general, I shall not doubt it. But even a liberal admits some exceptions, where true beliefs are a handicap. For instance the skater may be better off unaware that the ice is thin, the tightrope walker unaware that he is crossing a snake pit, the soldier unaware that the ground is mined. George may need his self-confidence and a doctor, who believes in improving people's insight, may be something of a health risk.

The point becomes less quirky in relation to desires, as opposed to beliefs. Having it borne in on him just how lonely, friendless and helpless he is can seriously damage George's will to live. The doctor cannot assess the situation by, so to speak, hidden camera and one-way mirror alone. He must interact with George, must probe his determination or apathy and, in short, must prod the roots of the plant to see how well they withstand prodding. This is also a comment on the earlier thought that George may be wholly clear about consequences but too diplomatic to say so: the doctor cannot act on the mere possibility that it is so. If George started with an unresolved mixture of hope for an independent life and weariness of a lonely one, he may well finish with a

newly defined wish to go home to die. To put it too starkly, no doubt, respect for persons threatens sometimes to mean killing them off.

It is rapidly becoming unclear whether we are concerned with George's wants or George's interests. Which of the two is indicated by the maxim that patients should be treated as persons? The easier answer is the economist's: let there be consumer sovereignty for George's *wants*. If he still wants to go home after becoming clear about the risks, then the doctor has no business to obstruct him further. A merit of the answer is that it avoids having to tangle with the awkward concept of interests. Who can say that it is in George's interest to drift on into an institutionalized decline rather than to shorten his loneliness by returning home? The doctor is to probe the difference between considered and unconsidered wants. Having established what George truly wants, he need not worry about whether the preferred outcome is in George's interests. Autonomy, in other words, goes with considered wants, not real interests. This is the liberal attitude which I had in mind for the initial question of how much self-determination George should be allowed. The doctor is not to set up as an authority on the riddle of existence: on that each patient is his own sovereign consumer.

The suggestion, generalized, is that the doctor's role should be patient-centred, with patients sovereign and doctors their servants. A death of one's own is the ultimate in consumer choice. When generalized thus, however, this version of liberalism runs into difficulty. I shall try to show first that patient-centredness is not a clear guide to action and then that, even when it is, it may not be a good guide.

A Scottish doctor recently landed himself in trouble by adopting a novel approach to the problem of when to stop treating senile patients who catch something lethal like pneumonia. He began taking instructions from his patients at an earlier age, when they were old and thinking about getting older. He asked them what they would wish done, if they became senile and the problem arose. Many replied firmly that they would wish to be allowed to die in those circumstances, and wrote it down as a, so to speak, penultimate will and testament. The doctor reasoned that, since one cannot consult patients with senile dementia, the next best thing is to consult their former selves. The British Medical Association, however, would have none of this. The responsibility for a senile patient, it said, is and must remain the doctor's. He should consult relatives but the presumption must remain that patients wish to live and that doctors are there for the purpose. The patient's younger self cannot be an authoritative voice.

The BMA was, I think, rather careful not to say too much. There are some discreet conventions about the withholding of treatment for patients where prospect of a fair quality of life is gone beyond recall,

and the BMA said nothing on this score. Its objection was to involving the patient's former self. It has to be an objection on behalf not of the patient's wants but of his interests. It is no good arguing that the senile patient would *want* to live on, if able to consider the matter rationally, since the problem arises only when the patient cannot consider the matter rationally. The objection has to be that the patient's earlier utterance mis-states the patient's later *interests*. The Scottish doctor might seem to have the stronger ground, if one believes that a patient-centred approach is to be one governed by the patient's *wants,* since he at least has an earlier statement of a *want* to go by. But one suspects that even he is not acting on the mere fact of a want expressed but on his own belief that death has become in the patient's interests.

Thus prompted, we should notice that the classic liberal spokesman on the sovereignty of the individual words the case in terms of interests. The argument of Mill's *On Liberty* is that it is in our *interests* to be left to pursue our own good in our own way (so long as we do not interfere with the liberty of others). In *The Principles of Political Economy* he maintains that individuals are the best judges of their own *interests*. This at once raises a question about whether individuals' *wants* are sovereign, when they conflict with their interests. Mill gives a clear answer—No. In *On Liberty* he insists that the only liberty worth the name is that of pursuing our own good in our own way and argues that neither legal nor physical force may be used to compel or obstruct this pursuit. But he has no scruples about applying social pressure to ensure that we use the liberty to achieve the individuality and autonomy, which he holds to be in our interests, whatever our foolish wishes to the contrary. In the *Principles* (Book V, Chapter 11) he considers seven exceptions to the general maxim that individuals are the best judges of their own interests and bids government take action in each of them to make sure that what is done is truly in individual's interests. Among them are cases where the individuals concerned are not mature and sane adults in full possession of their faculties, and where an individual attempts 'to decide irrevocably now what will be in his interest at some future time'. The Scottish doctor can still invoke Mill against the BMA but only by arguing that the senile patient's younger self remains a reliable guide to the *interests* of someone who has ceased to be a sane adult in possession of his faculties and whose 'own good' is to die.

Death is, in general, an awkward case for a liberal debate about what is in someone's interests. If death is the end of a person, then it closes his profit and loss account, making it hard to maintain that he will be better off, if he no longer exists. Even the thought that his life would be in the red, were he around to live it, becomes awkward with senile dementia. On the other hand, if death is not the end, then who knows how to adjust the profit and loss account for another world? Yet a fully

patient-centred approach would need a view on these enigmas. Perhaps that is why the Exit Society, which advocates euthanasia and helps people in search of a death of their own, cannot persuade the medical profession that doctors should be as obliging about death as about life. It is worth noting, however, that societies vary. In Holland, for instance, exits seem to be very much easier to come by—a fact worth noting not only because more old people are living on to a stage where life is a burden but also because AIDS will soon be reaping the young in numbers too large to be furtive about.

At any rate, my point is that a patient-centred approach cannot avoid tangling with questions of *interests* as soon as patients start wanting what is bad for their health. This is not to say that good health is always an overriding interest—doctors are sometimes asked to support people doing dangerous or exhausting tasks which shorten their lives. But no doctor is required to help masochists suffer more pain in the name of consumer sovereignty. The most libertarian version of a liberal-inspired patient-centredness on offer is one which gives the patient the benefit of the doubt when it is not clear that his wants are in his interests.

Patient-centredness is thus not the enemy of paternalism that one might suppose. It invites us to decide in the patient's interests but leaves the doctor often the better judge of them. All the same, I imagine that sympathies still lie with George, old, lonely, uncared for and wanting release. The first question was how much self-determination he should be allowed, given that his insight is poor. Treating George as a person will, I imagine, be held to imply only that the doctor should make sure that his insight is not so poor as to frustrate his clear interests. So far, presumably, George goes home.

But I have almost commanded this answer by asking about a single patient and exploiting the obvious attractions of patient-centredness as a guide to medicine. The other question was how much responsibility the doctor shoulders, if he colludes with George's wishes. A natural thought is that, if the answer to the first question is to give George the decision, then the doctor must be morally in the clear for the purposes of the second. But, on reflection, it is not so simple. Even a patient-centred approach saddles the doctor with moral responsibilities which are not exhausted by serving George's interests. I open my case by asking which patient is to be at the centre of a patient-centred approach.

It is time that the doctor had a name too. Resisting a revealing temptation to call him Dr Smith, I shall christen him Henry. (In what follows Henry is a hospital doctor overseeing George's treatment and discharge. But, since the moral relationship which I want to discuss is a professional yet personal one better typified by a GP, he can be thought of as George's GP also. This elasticity, I trust, will not spoil the

argument.) It is a trick of the example to suggest that Henry is involved only as George's medical adviser and that only Henry is involved in the decision. Henry has other patients beside George and belongs to a medical profession most of whose patients are not Henry's. Equally I blanked out other people concerned with George, notably the social services department, but they are still in the wings and they too have other clients and commitments. None of this matters to George, seeking the patient-centred solution which fits in with his wishes, but it is bound to weigh with Henry. Morally speaking, collusion will not be an isolated act.

George is occupying a hospital bed. There are other people waiting for beds and George does not really need one. At first sight this is not Henry's problem, partly because it is not his fault that there is a lack of outside support to keep George going and more generally because ordinary hospital doctors and GPs are not responsible for the overall allocation of resources. But this is too formal a way of looking at a doctor's responsibilities. If Henry is an experienced and respected GP, he has a *de facto* power to call up social service support or to secure hospital beds, while his credit remains good. His credit is staked on every case and depends on his not staking it too casually. He can mortgage it for any one patient but, if his fellow professionals do not agree that the case merited the resources by comparison with other cases, it will be that much harder for Henry to secure help for his next patient. Hence Henry's considered pronouncement on George may have costs and benefits to Henry's other patients. To serve *all* his patients he needs a good reputation among those who allocate resources which cannot meet all claims by all doctors. George, let us assume, simply wants the best result for himself. Henry aims more widely at the best for all his patients. These aims can conflict.

Moreover Henry is not solely the champion of his own patients. He has a doctor's concern for all the sick, shared with fellow doctors and with others in the work of promoting health. That opens up an interesting ambiguity in the notion of patient-centred care. Should each doctor care for his own patients (and, more broadly, each professional for his own parish)? Or should each behave as a member of a group whose aim is the good of all patients? These alternatives do not yield the same result. Just as Henry's 100 per cent effort on George's behalf may do what is best for George at the expense of Henry's other patients, so Henry's 100 per cent commitment to his own patients may be at the expense of other patients. Similarly, a powerful consultant, administrator or health team can get more than proportional resources for their own parish if their own parish is what counts. Patient-centredness is ambiguous on the point. Offhand one is inclined to say that the care a patient receives should depend not on who he is, where he lives or who

his doctor is, but on what he needs. That suggests a sort of Kantian universality, bidding us look on all cases evenly from some central vantage point. On the other hand, the obvious universal Kantian imperative to each doctor or carer is 'Do your best for your patients' and this comes with the tempting utilitarian thought that since each doctor has a personal bond with his own patients and each professional with his own patch, the total amount of good care resulting will be greater.

If Henry is an experienced, effective doctor who knows how to work the system better than most, then equality of patients' need seems to mean that he should *not* do his best for his patients. To block this odd conclusion, we might try envisaging the care network as a system of checks and balances. Henry is to do his best for his own patients but other professionals, with their rather different concerns, do their best to stop him getting away with unfair allocations. That offers a promising rationale for the division of caring labour, given an ideal allocation of resources (including professional skills). If the doctor can count on social work support but only when his request for it is reasonable in relation to other requests, then we perhaps have something like a game where each player can go flat out in the knowledge that enforced rules of fair play will stop him and others gaining unjust advantages. The best efforts of each in his own parish can then sum to the best which the system can deliver as a whole.

But this is to take a very idealized view of the social world about us. In George's case, it supposes that the social service department has proper resources, so that it can support George at no cost to its other more desperate clients, if the request for support is reasonable. In practice social service departments are sure to be stretched thinner than this. Being under-resourced and, most unfairly, the target of political suspicion or hostility, they can do a job which will withstand public scrutiny in case of disaster and official enquiry only if they take on less cases than ideally would be for the best. As I presented George's story, social services were offering some support but probably not enough to keep him going in earnest. Although this may have reflected their view that, given the lack of family and friends, he should stay in hospital, it may also have been because they could not spare the resources for major support, given the other claims on them. At any rate let us suppose it so and ask how that affects Henry's ethical responsibilities.

The general puzzle is one of professional duty in a world of imperfect compliance. It is not one of legal obligation, since Henry can see to it that his back is covered whatever he does. He can steer George either back home or back into his hospital bed and cover himself by the wording of his professional judgment. Ethically, however, we still want to know how much responsibility is his if he steers George home, knowing that the social work support really available is not really

enough. It is not his responsibility to provide enough support to free George's hospital bed with a clear conscience. But he has a moral decision to make and he is answerable for it in a way which George is not and which is not trumped by George's wish to go home. He might consider, for instance, encouraging George to go home partly because this is one way of putting pressure on those who allocate the budget to social services. This would be for the future benefit of others in need but hardly for the present benefit of George. This sort of consideration is endemic in the ethics of professional roles when played out among roles which mesh imperfectly, and it is one on which patient-centredness gives no guidance.

A final ambiguity about 'patient-centred' is found by asking whether it means 'answerable to the patient'. The initial reaction is probably that it does. The doctor–patient relationship is usually deemed one-to-one, in that it is a confidential relation of trust between a doctor and a patient with a right to his undivided commitment. But a couple of examples will show that there is more to it. In the days before syphilis was curable and Wassermann tests required before marriage, a New York doctor diagnosed syphilis in a patient and advised telling his fiancée. The patient refused. Recently (although it may be just a new urban legend) a London doctor diagnosed AIDS in a patient, who demanded utter confidentiality, and was presented a few months later with the man's unsuspecting wife, radiantly pregnant. Both women happened also to be patients of the respective doctors but this point only focuses the ambiguity about which patient to centre upon. The broader question is whether even a patient-centred practice is not answerable to a wider tribunal. The doctor is not like a priest upholding the secrecy of the confessional in the face of enquiries by the temporal authorities. He is an agent licensed by that state, akin less to a priest than to a social worker who is explicitly the state's appointee, wielding its authority even in seemingly personal relations with clients. The doctor is answerable to the community at large and, although it is relevant whether or not syphilis and AIDS are legally notifiable diseases, his professional conscience is not fully absolved by this test. How much responsibility does Henry shoulder if he colludes with George's wishes? The question is incomplete: how much responsibility *to whom*?

It has emerged by now, I hope, that if we try for something patient-centred, to the effect that the doctor's duty is to his patient, the idea is thoroughly ambiguous. Even concentrating on the particular patient of the immediate case we find that the duty is to serve the patient's interests as a person rather than his declared wants for his physical machine. Liberal notions of autonomy leave the patient's wishes the benefit of the doubt as a guide to his interests but override them when his insight is clearly lacking. Meanwhile patient-centredness cannot be