

the trouser pocket of the "investigator" since, as both the doctors' and patients' responses in La Puma and colleagues' study accurately report, "some doctors might be influenced to enrol patients just for the fee."

Proper, worthwhile research involving interesting new agents should not be confused with their marketing; in these two very different circumstances, the aims of the industry should also be recognised as distinct and separate. Supporting research before the licensing of the agent, the company clearly wishes to elucidate the potential value of its promising new drug—though recognising, of course, that overenthusiastic claims, particularly if there are hazards associated with the agent, could rebound on it in a damaging way. This expensive misjudgment has occurred on many occasions over the past 20 years. With marketing, however, the aim is quite different—neutrality is no longer appropriate, the commercial pressures are set full steam ahead, and the company naturally wishes to see the agent rapidly established. Development costs have to be recouped, and the aim will be to corner the market for as long as possible.

Should patients always be told if the prescribing

physician receives a fee? This difficult ethical issue would doubtless be resolved by answering a firm "yes," though this is certainly not common practice in Britain. Personally I would have no qualms about it—I'd feel better, though, if in the same breath I could point out that the whole of the sum would be used to support the departmental research programme. I would not expect patients to believe that a personal payment of, say, £1000 for entering them into a new drug programme would have no influence on my view as to whether or not they were "suitable." We're only human, after all—even the most dispassionate and academically minded of clinicians.

Perhaps this whole murky area is best viewed as another example of the somewhat uneasy relationship between academic departments (with research programmes to fulfil and enthusiastic young research fellows to support) and a pharmaceutical industry in which research and development considerations inevitably take second place to commercial hard-headedness. Nothing wrong with that, one might think; but it does leave a slightly bitter taste in the mouth.

Remembrance of conversations past: oral advance statements about medical treatment

Ann Sommerville

Polls show increasing public interest in advance statements or directives about medical treatment ("living wills") but that few people, apart from Jehovah's Witnesses, carry such documents. Patients' firm, witnessed oral decisions are often sufficient to aid clinical decision making but should still be recorded in medical notes. Without documentation, dilemmas arise when others claim to know patients' views on the basis of past unrecorded conversations and demand withdrawal of treatment when patients are not terminally ill and cannot speak for themselves. Legal and ethical considerations oblige doctors to act in the best interests of an incapacitated patient; these considerations are now formally defined in draft legislation as including consideration of the patient's past wishes. The practicalities of ascertaining the strength and validity of such wishes from conversations reported second hand are complex. The paucity of legal and ethical guidance on reported oral advance statements makes debate imperative and renders the alternative of having designated surrogate decision makers increasingly attractive.

At the end of May a case was scheduled to go to the High Court to clarify the circumstances in which legal weight should be given to remarks that people are said to have made, sometimes years before, about what they envisaged to be an acceptable or intolerable existence for their future selves. At the heart of the matter was how to interpret a conversation that G, a young woman now brain damaged, had had with her family while watching the television coverage of the Tony Bland judgment.¹ She reportedly emphasised that she would not want to be kept alive in similar circumstances but left no document refusing life prolonging treatment. G subsequently suffered severe disability but, unlike Tony Bland, is not in a persistent vegetative state.

The profound philosophical, psychological, and moral questions raised by the Bland case looked

set to recur against the background of a different diagnosis. It seemed that evidence might focus on issues of self determination rather than on decision making based on notions of the patient's interests, which was a prominent issue in the Bland case. (In fact, since the Bland case the sometimes polarised arguments for basing decisions on patients' previous wishes or on their best interests are increasingly merging. The Law Commission, for example, has defined patients' best interests as encompassing their previous wishes.²) Advance statements—oral, written, formal, or casual—were not, however, germane to the Bland case since the patient had never given any indication of his wishes, but the House of Lords took the opportunity there to state unequivocally that advance refusals of treatment resulting in the patient's death could be legally binding if expressed as "clear instructions."³

In the event, the long anticipated G case was postponed. Undoubtedly, however, a case based on an oral refusal will eventually go to court since opinion polls in Europe and North America indicate a growing public interest in advance decision making but a widespread reluctance to get to grips with the paperwork. Arguably, medical bodies should now consider the ethical requirements and evidentiary standards that need to be met for a reported oral advance refusal to be as morally and potentially legally determinative as a written document. This is not to presume that courts would necessarily consider oral statements to be on a par with written documents. For oral remarks courts may well demand greater evidence of the patient's knowledge and competence, of the reliability of witnesses, and of the long term consistency of the views reported. Currently, however, informed debate about principles and their application to medical practice is more pressing than second guessing the courts or analysing the specific details of any particular case. An incidental consequence of the postponement of G is that it allows the BMA, whose recently published code of practice on advance statements is largely non-

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committal on oral statements,³ to air these issues at its forthcoming annual meeting before the law becomes set.

Oral statements in medical practice

In this debate distinction should be made between the use of advance statements in daily practice and their quite separate role as evidence in the judicial system. Oral statements can also be of two types. On the one hand, they could be called formal, although unwritten, when they arise in discussion with health, legal, or care professionals, are witnessed by someone able to attest to the person's competence and knowledge, and are likely to be noted in some form by the witness. On the other hand, what can be termed conversational statements, such as those of G, rely solely on the memories of friends and are unlikely to be recorded elsewhere. In either case most decisions about relevance and applicability will be made in hospitals rather than courts and without necessarily raising problems for doctors or patients. Arguably, oral statements are and have always been an integral part of medical practice.

Non-resuscitation decisions, for example, often reflect patients' non-written views. Terminal care may entail discussion in advance with patients about their health management if they became confused or unconscious. Views recorded in medical notes and amended if the patient's opinions change generally suffice for treatment purposes. Other documentary proofs are superfluous in circumstances where the parties are clear about likely options and the limited time span within which they are implementable. If a patient is comatose or otherwise incommunicable information about his or her past wishes and values are among a range of factors considered as part of ethical decision making. Relatives' recollection of past conversations, even if not identified as a substitute advance directive, or "living will," give an important indication of the type of treatment the patient would want. Problems arise, however, if the reported comments conflict or, as in Tony Bland's case, the patient has never considered or discussed the relevant issues. For the practical purposes of providing appropriate care, a designated surrogate decision maker is arguably better for both doctors and patients than almost any form of advance statement. People who are uncertain or do not want to consider their likely fate in some unknown future situation nevertheless know that a spouse or friend would make the right decision. If one person has been nominated there is no dispute about whom the

doctor should address. American advance statements often simply nominate a family member or doctor to make decisions.⁴ An individual trusted by the patient can weigh the decision in relation to whatever is known of the patient's views rather than embarking on the procrustean exercise of stretching memories to match current circumstances.

Some legal issues

In the BMA's view a principal advantage of advance statements is the opportunity for informed dialogue with health professionals. This is forfeit if people decide alone or unreflectingly in response to some emotive event. Just as living wills are an imperfect substitute for contemporaneous discussion, so reported conversations are a poor replacement for written statements made in consultation with a doctor. Assessing the strength and validity of informal statements raises questions about the degree to which people really mean what they say and how selectively or otherwise their friends later remember and interpret conversations which were never written down or intended for public consumption.

Nevertheless, the fundamental legal basis of some advance statements is beyond doubt. Since the Sidaway case of 1985 it has been widely recognised in Britain that competent adults have a clear right to refuse medical treatment for reasons which are "rational, irrational or for no reason."⁵ Furthermore, in England and Wales it is now unambiguously clear in common law that competent and informed advance refusals of specified medical treatments can be legally binding on health professionals when certain basic conditions are met.⁶ The format of the statement has never been specified, so whether such refusals have to be in written form to be considered legally valid is unclear. Arguably, they do not need to be written so long as they are made by a person whose competence is not in doubt, are clearly established, and are applicable to the circumstances which subsequently arise.

In the case of *Re C*, for example, the court accepted the refusal of amputation by a patient in Broadmoor Hospital as having both current and future legally binding effect without his having to write it down.⁷ This could be called a formal refusal in that plenty of medical and legal witnesses documented his decision even if the patient did not. In that case it was held that a valid refusal of treatment required the person to comprehend and retain information, believe it in relation to himself, and weigh it in the balance to make a choice. The crux of the legal and moral arguments about advance oral statements may be how much the individual believed that a conversational comment about non-treatment would ever apply to him or herself. Arguably, to make a valid oral refusal people would have to understand that mental incapacity could befall them and that their oral refusal would result in treatments being withheld. For legal purposes not only would the person have to have had a clear intention when making the remarks but the evidence of that intention would have to be convincing.

Ethical and legal problems arise about the possibility of verifying whether the putative oral statement is a settled and informed decision or a chance remark. The time span between speaking and having the conversation reported may influence how it is recalled and the reliability and the independence of the witnesses may be open to question. American judges have tackled some of these problems, in what many see as a misguided manner, in the Nancy Cruzan case.⁸ Missouri State, where the case was first heard, had a strong policy favouring prolongation of life even when there is no hope of recovery, the assumption being that patients should be kept alive under all circumstances

unless there is convincing evidence of the patient's advance refusal. This presumption of an obligation to treat is not shared by British courts. It left the doctors in Missouri little decision making power in terms of prolonging futile treatment and required a standard of proof so exacting that few cases could hope to meet it. The Cruzan case shuttled between federal and United States supreme courts before Cruzan's friends could convince the Missouri court that past conversations were valid evidence of her firm decision that she would not want to be kept alive in a persistent vegetative state. Some commentators on the case saw some stages of the judgment as entirely out of touch with the reality of how people think and behave, and few would want to see British courts follow the Cruzan route.

As the BMA points out, there are considerable risks as well as advantages for patients making formal advance refusals of life prolonging treatment since under common law documents may be legally binding on doctors. If informal oral statements are to carry any similar weight, one implication is that people must give equal care to what they say as to what they write. Reliability in human terms and evidential terms could be quite different matters. Whereas it may be undeniable that certain words were said by a specific person on a particular occasion, the intention behind the statement is always likely to be more elusive. Not only do people often pre-edit their conversations to fit the sensibilities of the listener they are also more careful about comments that are likely to be quoted later than they are about throw away lines. Similarly, people hear and recall selectively even when the subject matter is of vital importance, as has been borne out by numerous studies showing that patients can recall little of the information given to them about their medical condition and proposed treatment.

How to make an advance directive

Currently, people can make an advance directive in various ways; such directives range from general to highly specific statements. There is no standard format (although legal firms increasingly have an eye on the business likely to be generated by do it yourself packs with a model form for a lawyer to countersign). One popular solution is that living wills should be subject to the same rules of validity as ordinary wills and testaments. According to this view, a person who seriously wishes to make an advance decision about medical treatment should register it in writing before a witness. Again American studies show that for elderly people in particular "consent procedures and detailed forms often work poorly to facilitate and ensure informed decisions on the part of the patient." Given the notoriously high proportion of people who die intestate, formalising treatment decisions in this way would undoubtedly reduce the number of advance statements made. But introducing obligatory legal hurdles does not solve the moral question of whether it is right to continue treating or keeping alive a person whose known wishes (although not documented on the correct official form) contradicted that action. Furthermore, mandatory bureaucratic procedures for writing an advance statement also imply the necessity of similar obligatory procedures to evoke it. A patient admitted to hospital who cannot obtain the correct withdrawal form or solicitor's signature may then be irrevocably fettered to his advance statement.

An alternative simple procedure could be to nominate a proxy decision maker. The Law Commission has proposed extending powers of attorney in this way and notes that in its consultation exercises, respondents with reservations about advance statements for health care were none the less enthusiastic about facilitating proxy decision makers. The House of Lords Select Committee on Medical Ethics, however, while recognising "the strong current of opinion in favour of proxy decision-making," did not favour development of such a system.¹⁰ Whether the Law Commission's proposals proceed depends largely on the report of the Lord Chancellor's Department, which is due to be published in September.

The BMA's advice on respecting patients' legitimate wishes, including those made in anticipation, has been reflected in its publications over several years, but the handling of conversational oral statements is still open to debate. To dismiss them entirely is to risk undermining the foundations of respect for patient autonomy. In reality the "majority of people do not anticipate the circumstances of their death with the exactness required under a clear and convincing evidence standard and do not plan their lives by creating formal legal instruments."¹¹ But to accept oral reports unquestioningly raises the possibility of abuse. Some argue that the courts with their adversarial approach are an inappropriate forum for discussion and that judges are no better than doctors at resolving the complex issues arising when patients are incapacitated and have left no formal statement. Nevertheless, guidance from some source is clearly needed for the public and medical profession alike. Oscar Wilde famously pointed out two tragedies of life: one being not to get your heart's desire and the other being to get it. Perhaps another, greater, tragedy might be getting what someone else imperfectly recalls as being your heart's desire.

Source of funding: No additional source of funding.
Conflicts of interest: None.

- 1 Airedale NHS Trust v Bland [1993] 1 All ER 859.
- 2 Law Commission. *Document 231*. London: Law Commission, 1995.
- 3 British Medical Association. *Advance statements about medical treatment*. London: BMJ Publishing Group, 1995.
- 4 Schneiderman LJ, Kronick R, Kaplan RM, Anderson JP, Langer RD. Effects of offering advance directives on medical treatment and care. *Ann Intern Med* 1992;117:599-606.
- 5 Sidaway v Board of Governors of the Bethlem Royal Hospital and Maudsley Hospital [1985] 1 All ER 643.
- 6 Re T (adult: refusal of treatment) [1992] 4 All ER 649.
- 7 Re C (adult: refusal of treatment) [1994] 1 WLR 290.
- 8 Cruzan v Director of Missouri Department of Health (1990) 497 US 261; Supreme CT 2841.
- 9 Herr SS, Hopkins BL. Health care decision making for persons with disabilities. *JAMA* 1994;271:1017-22.
- 10 House of Lords Select Committee on Medical Ethics. *Report*. London: HMSO, 1994.
- 11 Gostin L. Life and death choices after Cruzan. *Law, Medicine and Health Care* 1991;19(1-2):9-12.

(Accepted 7 June 1995)

Correction

Healthy eating: clarifying advice about fruit and vegetables

An editorial error occurred in this article by Carol Williams (3 June, pp 1453-5). In table II the last sentence of the rationale for including fruit juice should read: "Most of the intrinsic fruit sugars will have become extrinsic during extraction and become more carcinogenic [not carcinogenic]."