

The rights of the elderly

Who decides?

Meredith McLaine

The claiming of rights by the elderly who may depend on others for their day-to-day care may be the key to the proper recognition of the special needs of senior citizens.

She desperately wanted to get away from an overcrowded and conflict-ridden family situation in her daughter's household, but after moving in she felt she had made a bad decision. At her second interview Ms D was desperate, saying *'I'm not happy here at all'*. Her misery consisted of feeling lonely, bored, and useless. She did not like her room — it was too cold, both physically and emotionally; the bedding was 'dirty'. *The staff keep telling me I'll settle down. They won't let me do anything; they just tell me to rest and I don't want to . . . I went from one bad situation to another. I had to leave that place to get some peace, but I can't stay here, I can't stand it.*

Four and a half months later, Ms D said: *I'll stay here now. I might as well; there's no point in moving elsewhere . . . I feel this is less a place to live — more a place to wait to die.¹*

Ostensibly, the needs of older people who are no longer able to live fully independently are met by government and private provision of accommodation, health, and various community services. Thus these people become labelled 'dependent', and the common result is that their rights, over and above access to basic living needs, are forgotten or dismissed.

International sphere

None of the international human rights covenants refer specifically to older people. The Declaration on the Rights of Disabled Persons might be relevant in some circumstances, but reliance on this Declaration risks deeming older people, as a group, 'disabled' — which is precisely the kind of stereotype sought to be dispelled. Perhaps it is appropriate that the old are not categorised by human rights law. Instead, the discussion and practice of human rights should emphasise that the general rights possessed simply by virtue of status as a *person* are not diminished by old age. That the contents of, for instance, the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR) apply to the old as well as the young is obvious, but there needs to be recognition that for the old those rights are often particularly threatened

— whether it be because of ill-health, or various socially-constructed factors which impose a lowly status on old people.

This was the approach adopted at the 1982 World Assembly Conference on Ageing. Stressing the dramatic ageing of the world population, this meeting arrived at a unanimous resolution — the 'International Plan of Action on Ageing', now administered by the UN Centre for Social Development and Humanitarian Affairs. Rather than create actual new rights, this document aimed to draw the attention of governments to the needs of older people, establish goals, and provide financial assistance for developing nations through a Trust Fund for Ageing.

Two aspects of this Conference and Plan are particularly striking. One is that most of the discussion dwells on economic and social rights, with civil and political issues receiving only the barest mention. While health care, housing and income are perceived as crucial issues for older people, the associated problem of lack of decision-making power in determining policy for their own living standards and enforcing their rights is neglected. Repeated mention is made of lack of respect and status for the old, but these are treated as contributory causes of poverty and other socio-economic problems, rather than making the point that self-determination and dignity are themselves fundamental human rights.

The distinction between the sorts of rights separated into the ICCPR and the ICESCR is in some senses somewhat artificial, as low socio-economic status is frequently linked to lack of political strength. Nevertheless, the distinction does have practical consequences. For example, the World Assembly's emphasis on economic and social rights for old people is echoed by traditional aged-care policy in Australia, the focus of which tends to be on welfare through pension and health services, with — at least until very recently — little or no official recognition of the rights of old people to make their own decisions or participate in public life. Generally thought of in terms of benefits, welfare or even charity, aged-care policy has rarely been considered to involve human rights issues at all.

The World Assembly Conference also emphasised contrasts between the status of older people in western and non-western cultures. To generalise, the extended families and village communities of non-western rural societies tradi-

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tionally honour and esteem their elders. In contrast, capitalist ethics have comparatively little respect for old age, due to 'the undue emphasis the industrialised world has placed on the concept of productivity, and on the remorseless disposal of assets, both human and material, once their usefulness has been exhausted'.²

Thus in the west a person is deemed no longer of worth to society on attaining a cut-off age at which retirement and community expectation relegates him/her to automatic dependency on bureaucratic social assistance. Old age becomes a constructed, imposed category of difference and dependency.

Non-institutional care in Australia

If the concept of civil and political rights for old people is to be strengthened, it is important to stress that most older people are healthy enough in mind and body to manage their own affairs as independently as anybody else. However, for a substantial minority ill-health does affect the capacity to live independently. There is a tendency, as a result, for other people to exaggerate the extent of that person's dependency, and to strip him/her of almost all opportunities to think and act autonomously.

While, of course, not the only disease that reduces independence in old age, Alzheimer's disease has a particularly severe and long-term impact. Alzheimer's disease is estimated to affect 5% of Australians aged between 65 and 70, 10% between 70 and 80, and 20–25% of people over 85.³ Present government policy aims to decrease reliance on institutional care for dementia sufferers in favour of family-based care assisted by community services. While this is basically a worthy goal, reliance on 'the family' raises many problems. For one thing, it is just not feasible to expect that every older person in need of care has the option of living with relatives. At present, it is estimated that one-quarter of Alzheimer's sufferers live on their own. And while this figure is alarming, family-based care itself must not be idealised. The strain can adversely affect both carers and patient, exacerbating or flaring family tensions. Even where tensions are not obvious or dramatic, families often impose condescending limits on the freedom of their older members. The results for the older person are feelings of frustration and little self-worth. Australian/Anglo-Saxon cultural norms, furthermore, tend to regard having an

old, unwell person living in a family household as slightly embarrassing, shameful and intrusive. Hence that person is likely to feel that she/he is a burden. Surveys suggest that the majority of older people do not want to live with family, greatly preferring the independence of living alone wherever possible.⁴

Various forms of what is loosely termed 'elder abuse' can occur within the family — domestic violence for instance — inflicted either by a spouse, or by other relatives frustrated by the struggle of living with a chronic dementia sufferer. Older women are particularly vulnerable to both physical and psychological abuse, often having a low household status, and rendered subordinate to relatives by lack of financial independence. It is sometimes the case that husbands or adult children living at home demand that the same domestic chores be performed for them as in the past, refusing to recognise or make concessions for illness.

Placing responsibility behind closed doors thus creates a conflict of interest between rights to privacy on the one hand, and government regulation of health care and human rights on the other. Arguably, too, for the community to force the responsibility of caring for the aged onto private individuals is neither fair nor realistic. For example, the assumption that women are home all day to provide full-time care is a fiction rendered increasingly unrealistic as more and more women enter the workforce.

The ideal of family-based care also overlooks particular groups — one being the homeless old; another being the large numbers of older people in public hospitals who have nowhere else to go. Geriatric hospital wards can become 'de facto nursing homes',⁵ unrecognised as such and free of the law applying to standards of living in residential institutions.

Institutional care

For residents of nursing homes the human rights to be treated as individuals and with dignity are, potentially, greatly threatened. This is also the case in older people's hostels, boarding houses and retirement homes, with the severity of the problem varying according to the degree of independent living catered for by the institution.

The relationship between a hospitalised patient and the people treating him/her is traditionally one of submissiveness on the part of the patient

towards paternalism and authoritarianism. This situation is exacerbated by the low self-esteem of nursing home residents, and by the stigma attached to nursing homes as 'warehouses', storing people for whom the world no longer has room. In the past, nursing home care could easily be of minimal standard. There was little accountability required of these institutions with their roots in charity — patients were expected to be grateful for being cared for at all.

Despite increasing regulation of standards, residents still tend to take a resigned attitude to dissatisfaction or discomfort, in preference to being labelled a 'troublemaker' by staff resentful of special requests or complaints. Although officially the residents are there by choice, often that choice was made by relatives or authorities — and, in effect, custody and compulsion (both psychological and physical) pervade every waking moment of the unhappy resident. The symbolic power of the nursing home as spectre is seen in the dread displayed by hostel residents — desperately trying to hide signs of declining independence — of being transferred to attached nursing homes.⁶

There are incidences of blatant abuse or neglect of patients. However, to focus on these is to ignore the multiplicity of everyday problems which affect every nursing home resident. Human rights breaches arising from entrenched daily routine tend to be subtle, and thus hard to establish and sanction. They include: lack of individual choice regarding, for instance, diet, time of eating, sleeping and rising, clothing and decoration of surroundings; lack of privacy; lack of control of personal finances, mail, and medical treatment; constant noise; sheer boredom, and feelings of utter uselessness. Less universally experienced, but nevertheless common, are restriction of movement via physical harnesses and tranquillisers. For ethnic residents the situation is aggravated by language barriers and failure of institutions to cater for differences in cultural practice. Overall, the nursing home resident can be subjected to constant condescension and regimentation, and hence to a perpetual assault on dignity.

During the past 10 or 15 years formal implementation of resident participation in the running of Australian old age homes has increased, together with establishment of independent advocacy services.⁷ With the publication of the Commonwealth Nursing Home Outcome Standards in 1987 significant

steps were taken towards enshrining uniform standards of care.⁸ A code of practice for staff, this is internally enforceable by the Department of Health, Housing and Community Services. Residents themselves have no power of enforcement.

These standards, and particularly their emphasis on the rights of the individual, were the basis for the Charters of Residents' Rights and Responsibilities for Nursing Homes and for Hostels.⁹ Allegedly the first of its kind in the world, this subordinate legislation defines comprehensive rights which are personally enforceable by residents. In a form akin to international human rights instruments, the Charters prescribe rights based on individuality, dignity, privacy, informed consent, freedom of choice and of movement, and participation in decisions affecting personal affairs and daily management of the institution. Although fairly broad, the Charters' contents are clear and comprehensive rather than vague or trite. A separate document, 'the Agreement', provides for enforceability of the principles in nursing homes (but not yet in hostels). Effectively a standardised contract, which may (but not 'must') be entered into between the proprietor of the nursing home and the resident, it contains detailed conditions for practical adherence to the Charter.¹⁰

As the Charters were released in 1991, the speed and success of the implementation of these rights remains to be seen — and will inevitably be hampered by the various conflicts of interest involved in nursing home management. For example, individual rights can conflict with the needs of the residential community considered as a whole. Similarly, the rights of the staff to decent working conditions and freedom from harassment are undermined by the small minority of residents whose behaviour is offensive. The most problematic issue, however, is that of balancing the rights of autonomy with the rights to safety and security, and the staff's duties of care. The Practical Guide to the 1987 Outcome Standards discusses this matter in detail,¹¹ concluding that if the resident wants to take a risk dangerous to his/her own welfare, and unless she/he has been declared legally incompetent, the resident cannot ultimately be prevented from taking the risk. Staff have a strict obligation to strive to ensure that the person understands the dangers of the decision, and to try to persuade him/her of its undesirability, but this 'persuasion' must not involve force or coercion:

If a person is frail or sick, or . . . somewhat confused, this is no justification for having those aspects of daily living tightly controlled by others who want to protect them . . . Risk-taking is a part of everyday life as are the occasional minor injuries associated with risk-taking. The satisfaction which is derived from facing and conquering risks is necessary for human growth and development and is a source of satisfaction and dignity.¹²

In hostels, where residents are less dependent than those in nursing homes, the principles of the above quote are generally able to be readily adhered to. A spokesperson for the staff of one Sydney hostel is adamant that management policy has dramatically altered in the last year or so — with residents able to 'smoke, drink, have breakfast in bed, sit outside when it is cold if they want to . . .' and so on. For the staff of nursing homes, however, caring for very frail or mentally unstable patients, administering the new approach is unlikely to be quite so straightforward.

Despite the obligation that proprietors distribute copies of the Charter to every resident, there is no guarantee that all residents comprehend their rights. Where they do understand, methods of enforcement might prove difficult. While theoretically the rights are enforceable through the court system, the ministerial circular attached to the Charter advises that 'it is not intended or expected that, if disputes arise . . . this will necessarily lead to litigation'.¹³ Advocacy services providing dispute resolution through negotiation and conciliation are to be expanded, but these cannot automatically overcome the reluctance of residents to make complaints. Proving that the grievance is justified might also be an obstacle for residents — as suggested by the fact that, in 1989-90, only 32% of complaints received by the Department's User Rights Section were held substantiated under the Outcome Standards.¹⁴

Within the nursing home industry pockets of resistance to the Charter remain. The announcement of the proposed legislation in November 1990 caused an uproar fuelled by the opposition of the Catholic Church to the rights of respect for residents' sexual needs, and to choose one's own doctor; the latter grievance based on fear that euthanasia could result. The Anglican Church subsequently voiced support for the Catholic stance on the sexual issue, and the government was forced to remove this clause altogether.¹⁵ The objections are indicative of typical conflicts

encountered by human rights law generally — for instance, different perceptions within the community as to the nature of human rights:

. . . the conscientious objection to signing which the Bishops advise is precisely to uphold more stringent standards of respect for human life and dignity than are required by law.

Catholic Archbishop of Sydney¹⁶

and resentment of the law's interference in matters regarded as private or as sacred to personal conscience:

We view with great concern the increasing intrusion of government into the lives of people. Religious institutions have shown themselves over the centuries to be devoted to the lives of people. This attempt by the government to deal with a non-problem puts another nail in the coffin of community freedom.

Dr Bruce Shepherd, President,
Australian Medical Association¹⁷

The Charter and Agreement have potential to enshrine residents' rights as a crucial and normal aspect of life in old age homes. Nevertheless, while human rights for residents of old age homes continue to be considered a 'non-problem' in some quarters, breaches will continue to occur. The existence of the abuse which the Charter fundamentally seeks to prevent, that of imposed control over the individual's body and mind, is unwittingly confessed to by the Little Sisters of the Poor with the following comment on sex in nursing homes:

We would allow it but not in our homes. We would say they have the right to do it but we do have the right to decide to choose.¹⁸

References

1. Montague, M., *Ageing and Autonomy — Who Makes Decisions for Older People in Supported Accommodation?*, Fitzroy, 1982, pp. 112-113.
2. Selby, P. and Schechter, M., *Ageing 2000 — a Challenge for Society*, Lancaster, 1982, p.17, p.194.
3. NSW Department of Health, *Directions on Ageing in New South Wales*, Sydney, 1990, p.16.
4. See generally, Dempsey, K., 'The Marginalisation of the Elderly: An Australian Case Study', (1990) 9(3) *Australian Journal on Ageing*, pp.12-18, at pp.12-13.
5. Dempsey, above, p.14.
6. See Minichello, V., 'Admitting Nursing Home Residents: A Case Study in Policy Implementation' in Kendig, H. and McCallum, J. (eds), *Grey Policy — Australian Policies for an Ageing Society*, Sydney, 1990.

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or her standing in the matter? (c) For what purpose is the information required? (d) What information is in the doctor's possession? (e) What part of the information is relevant to the matter in hand? (f) To what extent is the information already known to other parties? (g) What is the likely effect of disclosure on the patient? (h) Is there any overriding claim in the public interest?³⁷

References

1. *Confidentiality Guidelines: Health Records and Data Collections*, October 1991, Department of Health (hereinafter *Confidentiality Guidelines*). At the time of writing these Guidelines were in draft form, awaiting distribution and comment.
2. *Australian Health and Medical Law Reporter* (CCH) para 27-800. There is a possible exception with regard to medical reports ordered by the doctor to assist the doctor in diagnosing the condition of the patient (for example, pathology reports, X-Rays). Such reports are probably the property of the patient, particularly where the reports have been paid for by the patient or his/her health fund. See *Australian Health and Medical Law Reporter* para 27-800.
3. See *Confidentiality Guidelines*, above, at 9.
4. See *Report on Confidentiality of Medical Records and Medical Research*, Law Reform Commission of Western Australia, 1990 at 4.
5. Dix, A. and others, *Law for the Medical Profession*, Butterworths, Sydney, 1988, at 66-67.
6. See Skene, L., *You, Your Doctor and the Law*, Oxford University Press, Melbourne, 1990 at 258 ff 1 referring to *Privacy Act 1988* (Cth) and for Tasmania, Pt IX (Discipline and Conduct) of the *Tasmanian State Service Act 1984*, s.54(1)(i) and s.32 *Health Services (Conciliation and Review) Act 1987*.
7. See *Australian Health and Medical Law Reporter*, above, at para 27-760.
8. See Skene, above, at 146.
9. See generally *Report on Confidentiality of Medical Records and Medical Research*, Law Reform Commission of Western Australia, above, Appendix II at 21-23.
10. Skene, above, at 146.
11. In Tasmania the law with regard to defamation is contained in the *Defamation Act 1957* (Tas.).
12. See s.5 of the *Defamation Act 1957* (Tas.).
13. See s.17 of the *Defamation Act 1957* (Tas.).
14. See Dix and others, above at 68ff, where it is suggested that the doctor in whom the confidence was originally vested would also be liable.
15. See *Australian Health and Medical Law Reporter*, above at para 28-960.
16. See above text accompanying refs 12 and 13.
17. Consent may even be explicit as a result of forms signed by the patient on admission to hospital. It has been suggested that where the consent is not explicit, the fact a person seeks treatment at a hospital would in itself be an indication of implied consent. For some authority for this 'need to know' principle, see *City of Birmingham District Council v O & Aor* (1983) 1 All ER 497, though not specifically dealing with medical records. Query the position with regard to mentally disturbed patients and compulsory detention. If the patient is incompetent to give consent, consent would have to be sought from the patient's legal guardian or other person vested with the authority to give consent.
18. See also the recommendation made in the *Confidentiality Guidelines*, above, at 16.
19. See Lord Denning in *Attorney-General v Mulholland* [1963] 2 QB 477.
20. See s.96(2A) of the *Evidence Act 1910*, as amended, which provides that no physician or surgeon shall without the consent of his patient, divulge in any civil proceeding any communication made to him in his professional character by such patient, and necessary to enable him to prescribe or act for such a patient unless the sanity of the patient is the matter in dispute. Similar legislation exists in Victoria and the Northern Territory.
21. See *Australian Health and Medical Law Reporter*, above, at para 39-219ff.
22. See *Report on Confidentiality of Medical Records and Medical Research*, Law Reform Commission of Western Australia, above at 3-4, also 24.
23. See *Australian Health and Medical Law Reporter*, above at para 27-770.
24. *Furniss v Fitchett* (1958) NZLR 396 at 405.
25. See Dix and others, above, at 75-6.
26. *W v Egdell* (1989) 2 WLR 689, Scott J at 713.
27. But see *Brown v Brooks & Ors*, unreported decision of the New South Wales Supreme Court, 18 August 1988, in which the plaintiff sought an injunction to restrain a clinical nurse from divulging information to the police regarding the sexual assault of his step-daughter which had been disclosed during counselling. The injunction was refused. Whilst acknowledging that there is a degree of public interest in maintaining the confidentiality of medical consultations between patients and their medical advisers, the court held that it was contrary to public policy to enforce a right of confidentiality which would impede the investigation of a serious crime. See discussion in *Australian Health and Medical Law Reporter* para 27-770.
28. See *Confidentiality Guidelines*, above at 14.
29. See Skene, above, at 120ff.
30. Hospital circular No 24, 6 April 1989. See Sparrow, J.M., *Availability of medical records to legal practitioners and others*, Department of Health, Tasmania.
31. *Freedom of Information Act 1982* (Vic.). See also the *Freedom of Information Act 1989* (NSW), *Freedom of Information Act 1989* (ACT) and *Freedom of Information Act 1982* (Cth).
32. See s.33(4) *Freedom of Information Act 1982* (Vic.).
33. See Skene, above, at 122.
34. See Commonwealth Law Reform Commission, *Privacy Report*, Vol. 1 p. 416 referring to the systematic breach of the legal rules.
35. See also above text accompanying refs 17-18 under the heading express or implied consent as an exception to the duty to maintain patient confidentiality.
36. See Dix and others, above, at 78 and *Australian Health and Medical Law Reporter*, above, para 27-750.
37. See Dix and others, above, at 78, citing France, R.D., 'Confidentiality' (1981) 283 *British Medical Journal* 197.

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7. The Accommodation Rights Service Inc., Sydney, for example, and see Hayman, A. and Howe, A., 'Client Participation and Advocacy in Geriatric Assessment', (1988) 7(2) *Australian Journal on Ageing*, pp.15-22, at pp.15-16.
8. See McDonald, T. and Bates, P.W., *Commonwealth Nursing Home Outcome Standards — a Practical Guide to Duty of Care*, Department of Community Services and Health, Canberra, 1989.
9. Department of Community Services and Health (Cth), *Charter of Residents' Rights and Responsibilities in Approved Nursing Homes and Hostels*, Canberra, 1990.
10. The Agreement is based on a model contract proposed by Chris Ronalds: see *Residents' Rights in Nursing Homes and Hostels: Final Report*, Department of Community Services and Health (Cth), AGPS, Canberra, 1989.
11. McDonald and Bates, above, pp.19-31.
12. McDonald and Bates, above pp.27-28.
13. Circular attached to Charter.
14. Department of Community Services and Health (Cth), User Rights Complaints Unit, *Annual Report*, May 1990, p.13.
15. Spokesperson for the Department of Community Services and Health, User Rights Section.
16. *Catholic Weekly*, 2.1.91.
17. *Catholic Weekly*, above.
18. *Daily Telegraph Mirror*, 2.11.1990.

TORTS

The New South Wales Committee of the Alternative Law Journal is considering an alternative examination of the current law of torts for the April 1993 issue.

- new torts, e.g. discrimination
- gender and torts
- teaching of torts
- purpose of tort law and alternatives to it.

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