

## Resolving conflict in end-of-life care

*We need to acknowledge the inevitability of death to have some choice in the manner of our dying*

The tragic story of Maria Korp, the Victorian woman with severe irreversible hypoxic brain damage after an alleged murder attempt, has been prominent in the Australian media over the past few weeks. The clear, considered, and humane intervention by the state's Public Advocate to authorise the cessation of artificial feeding has drawn both widespread praise, and some condemnation, especially from right-to-life activists.<sup>1</sup> Once again, care and decision-making at the end of life is in the public arena.

Earlier this year, world media attention focused on a young American woman, Theresa Marie Schiavo, who had been in a permanent vegetative state for more than 15 years. A prolonged legal and political battle in state and federal jurisdictions of the United States eventually led to the cessation of tube feeding, and her death. Interestingly, there was broad agreement between the courts and medical opinion that feeding should stop.<sup>2</sup>

In the preceding November, a much less publicised case was played out in Australia. The Supreme Court of New South Wales ruled that treatment could be withdrawn from Isaac Messiha, a man whose life was supported by ventilation and tube feeding, after he had experienced severe cortical brain damage resulting from a cardiac arrest.

Faunce and Stewart review the *Messiha* and *Schiavo* cases concerning treatment abatement (a term adopted by Weir<sup>3</sup> to encompass both stopping and not starting treatment) for incompetent persons (page 261) and weigh up two options for dispute resolution: an institutional clinical ethics committee ruling, and a judicial declaration on futility.<sup>4</sup> Although both may occasionally have their place, basic process questions need to be posed by clinicians<sup>5</sup> (Box 1) before recourse to external arbitration.

It is noteworthy that in neither case was an advance directive in place. An important difference between the two cases lies in the time that elapsed after catastrophic hypoxic brain injury before treatment abatement was considered — years for Theresa Schiavo, and initially only 4 days for Isaac Messiha. It is clearly essential that abatement decisions should not be made prematurely. They should only be made after the patient's failure to improve has been demonstrated over a period of observation and care that is widely agreed (by appropriate specialist neurological opinion, and supported by any relevant clinical evidence) to be reasonable for the diagnostic category concerned (stroke, post-coma unresponsive state, or brain death).

Patients in a post-coma unresponsive state (previously known as permanent or persistent vegetative state) constitute a small subset of those who are incompetent to make medical decisions for themselves, and can be further subdivided into those whose condition is the end-stage of a terminal (albeit slowly progressive) illness (for example, the Victorian *BWV case*<sup>6</sup>), and those who are the victim of anoxic insult or trauma and are being maintained by nutritional support indefinitely, as in the *Messiha* and *Schiavo* cases, and the United Kingdom case of Anthony Bland.<sup>7</sup> Leaving questions of advance directives to one side (their uptake rate has been poor nearly everywhere), Australian health legislation is not obviously helpful with the *Bland*-type

cases, whereas some headway has been made with the first subset, as seen in the *BWV case*, and the drafting of the *Consent to Medical Treatment and Palliative Care Act 1995* (SA).

Whether the underlying condition is progressive or static, nobody should be locked indefinitely into an existence on life support, often without consent, and usually with no prospect of recovery. Treatment abatement decisions for those who are unable to speak for themselves should usually be resolved where they traditionally have been, between clinicians and families or duly appointed agents. Recourse to public tribunals and courts should be minimised, reserved for situations of intractable disagreement, if only because such processes address, but can also encourage, adversarial style mediation.

Reducing the amount of futile medical treatment and introducing the timely deployment of appropriate palliative care to all who need it should be our preferred process. In bioethics, the concept of "futile" treatment has had a rough ride, mainly because of the inevitable uncertainties of medical prognostication. However, the "prognostic paralysis" described by Murray and colleagues is a real challenge,<sup>8</sup> and we cannot ignore the fact that medicine has its limits.

Despite polls reporting a widespread public pragmatism about death and dying ("I would never want to be a vegetable", "When my time comes I do not want to be kept alive artificially"), when clinicians do try to discuss treatment abatement with patients and families, they often meet disbelief, even hostility. Clearly, polls reflect public attitudes as distinct from personal situations. In personal health care encounters, the idea that cure is improbable or impossible, or that continued life support is inappropriate or unkind, is unacceptable to many families. The wider problem here is that acknowledgement of the inevitability of death, and preparation for it, have largely lost their place in

### 1 Key questions to be addressed by a health care team if treatment abatement is considered

- Are the clinical facts of the case well established? Is the diagnosis correct?
- Has sufficient time elapsed to be reasonably confident that there is no reasonable prospect of substantial improvement or recovery?
- Is there consensus among the clinicians about the diagnosis, prognosis and most appropriate course of medical action? Is a case conference necessary?
- Identify the key decision maker(s) in the family, or friends.
- Have the patient's family, carer(s) or legally appointed agent been advised of the above? Have they had a chance to express their opinions, and been involved in the decision-making process?
- Has the patient's general practitioner been involved?
- Has the abatement decision been documented? The plan for implementing it may involve a "time trial" of continued life-sustaining treatment. How will subsequent objections to the decision be dealt with?
- Has a consultative palliative care team referral been considered?♦

## 2 Goals of health-promoting palliative care

- Provide education and information for health, dying and death
- Provide both personal and social supports
- Encourage interpersonal reorientation towards a "natural" death
- Encourage reorientation of palliative care services towards public health ideas of prevention, harm-reduction and community participation
- Combat death-denying health policies and attitudes ♦

## 3 Goals of care

### Curative ("beating it")

- Cure or durable remission
- Prognosis: years

### Palliative ("living with disease, anticipating death")

- Disease incurable and progressive
- Prognosis: weeks, months (but can be years)

### Terminal ("dying very soon")

- Death imminent
- Prognosis: hours or days

Modified from Ashby and Stoffell.<sup>12</sup> ♦

our culture. For many, an almost child-like faith in medicine and science has taken its place.

We need to take up the challenges, and solutions, offered by health-promoting palliative care (Box 2).<sup>9,10</sup> We need to shift from seeing the treatment of dying people, and the maintenance of those who are permanently unconscious but biologically alive, as "curative". Instead, treatment of dying people with curative intent should be seen as an inappropriate and unkind obstruction of the natural dying process (given that our *natural* biological inheritance is to die) and a misuse of medicine.<sup>11</sup> Thus, we should first try to save the lives of those who are sick and injured, but when this is no longer a reasonable prospect, the goals of care need to reflect that reality (Box 3).<sup>12</sup> Mere emphasis on individual choice, important as it is, is not enough. A wider social understanding about the anticipated results of treatment of the dying and comatose person is essential, not medical heroics or legal and moral gymnastics. Health care workers and society need to move beyond curative domination and a view of death as medical defeat or failure. We need to question the place of death in the culture and processes of hospitals and aged care facilities, where most of these treatment abatement decisions occur. Appropriate care and decision-making at the end of life can only occur when death and the dying process are acknowledged, worked with, and regarded as an integral part of modern health care.

Research into policy-based approaches, such as advance directives<sup>13</sup> and care pathways for the dying in hospitals,<sup>14</sup> is important. Results of their evaluation in Australia are eagerly awaited. In the meantime, many hospitals in Australia still do not have adequate consultative palliative care resources. When in place, and adequately funded, they can assist with imparting

bad news, adapting to impending death, providing holistic care for patient and family, and with the transition, where appropriate, to community-based palliative care, or a palliative care bed. Evidence concerning good practice in communication about these issues is now well established.<sup>15,16</sup>

Death and dying is everyone's business. Good clinical practice, integrating all we have learnt about communication and support for patients and families facing death, will go a long way to easing these tough journeys. But clinical approaches are not enough. We need to work with the policy-makers to place death and loss back on the public health and community agenda. We cannot control the fact of death, but we can have some influence on the manner of our dying. Medicine can make a wonderful contribution to quality of life until death; and it can make it miserable. This choice is ours.

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