

# BOOK REVIEW

LINDY WILLMOTT\*

**Roger S Magnusson, *Angels of Death, Exploring the Euthanasia Underground* (Melbourne University Press 2002) pp vii-xvii, 1-325**

The death of Nancy Crick earlier this year generated enormous public interest. The circumstances surrounding her death fuelled the public debate on assisted death and euthanasia. The right to life proponents argued that the case graphically highlighted the immorality of shortening life, while many of those supporting a person's right to die saw Nancy Crick as an articulate and persuasive proponent of their cause. Emotions ran high and public opinion was polarised.

Assisted death and euthanasia are complex issues. They are issues about which most members of our community have strong views. In a democratic society, lawmakers are influenced by community views, and rightly so. However, in this important debate, the question that must be asked is the extent to which these differing community views are informed by existing medical and social practice. Are the views informed by an appreciation of the experiences of those who are suffering, and those who care for them? Magnusson's book, *Angels of Death: Exploring the Euthanasia Underground*, seeks to inject reality into the euthanasia debate by informing readers of what is actually happening within our community. The book draws on the information gathered over a three year period from 49 interviews conducted mainly with health care workers based predominantly in Sydney, Melbourne and San Francisco. Those interviewed were doctors (19), nurses (17), therapists (psychologists and counselors (7)), community workers (5) and a funeral director. Most of the interviewees worked principally with patients suffering from HIV and AIDS.

The opening chapters of the book (Chapters 1 – 3) describe the experiences of health care workers dealing with dying patients on a daily basis. These chapters also canvass the positions taken by those in Australia, the United States and the United Kingdom who have been outspoken in the debate, and whose actions have, in some cases, subjected them to criminal sanction. Magnusson also reviews recent surveys of medical practitioners and the general public, and the public stance taken by various key groups and individuals such as the peak medical associations, politicians, right to die societies, the churches and the media.

In Chapter 4 'Sanctity of life: the slow death of an idea', the author explores how we, as a society that holds sanctity of life as fundamental, are now struggling with the issues of

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\* BCom(UQ) LLB(Hons)(UQ) LLM(Hons)(Cantab), Associate Professor, Faculty of Law, Queensland University of Technology.

assisted death and euthanasia. Magnusson notes the evolution of the definition of death to include 'higher-brain' death, and the recognition of the appropriateness to withdraw life support to a person in such a condition. He also refers to the legal right of a competent adult to refuse life saving medical treatment, and the lack of criminal sanction for medical practitioners who administer medication that hastens death in circumstances where their intention was to provide relief from pain and suffering. The author suggests that assisting in a patient's death at that person's request may, in some ways, be regarded as 'the next logical step'. Magnusson then briefly considers some statutory responses to this issue – the now overturned Northern Territory legislation, and the statutes operating in the Netherlands and Oregon and now in Belgium.

Chapters 5 - 7 provide an interesting perspective on how and why patients seek assistance to end their lives; how health care workers respond to those requests; and the various ways euthanasia takes place. Interestingly, the interviewees articulated many reasons that influenced their decision to terminate their life. While 'intolerable/unresolved/chronic pain or physical discomfort' was the most commonly cited factor motivating a request for assistance to die, many identified the 'fear of process of dying/not wanting to suffer as others have suffered/fear of suffering when dying', 'tired of fighting/exhaustion and hopelessness' and 'severe deterioration in quality of life/lack of quality of life/unable to enjoy life' as factors in the decision.

Chapter 9 'The underground community' gives an interesting insight into the euthanasia network within the HIV/AIDS community. The interviews indicated that the health care workers and the funeral director who were prepared to assist those suffering from AIDS related illnesses were well known within the community. Information was readily available to patients who wished to discuss the possibility of receiving assistance to shorten their lives, should that be the course that they ultimately wished to pursue.

The final chapters of the book deal with other issues of concern that were highlighted by the interviews. Many of these issues arise from the fact that euthanasia is currently practiced in legally dubious circumstances. Because of the lack of regulation, there is a lack of quality control over euthanasia practices. Some health care practitioners may not be using practices to bring about death in the most peaceful way for the patient and, in some cases, so called 'cowboy operators' continue to practice unchecked. The author also raises concerns about non-consensual euthanasia taking place, and the danger of those working in the area suffering from burn-out. Those who assist others in their death are not only working in emotionally draining situations dealing with the sick and dying and their family and friends, but in circumstances where there is always the risk of prosecution.

In the final chapter entitled 'Euthanasia policy', Magnusson suggests that there are five different responses to the many complex issues highlighted in the earlier chapters: choose to ignore the survey data by casting doubts on the veracity of the data collected; do nothing and allow current practices to continue; accept that euthanasia (and assisting others to die) does occur and give more attention and resources to the enforcement of the law and the prosecution of offenders; legalise and regulate voluntary euthanasia and assisting a suicide; or, in the absence of such legislation, improve in some other way current illicit practices. While acknowledging that there is no one easy solution to the complex dilemmas that arise, the author suggests that, in his view, the appropriate way

forward is the enactment of legislation that attempts to regulate euthanasia practices. Magnusson is guarded in his recommendation and is quick to recognise the difficulty of the task of setting criteria to determine the nature of the disease, illness or suffering (if any) that must exist before a medical practitioner is permitted to assist in a patient's death, and to determine the necessary safeguards to be built in to the patient's decision to end their life, such as requiring the decision be considered by an independent medical practitioner.

By drawing on the accounts given by the interviewees, the book raises important issues in the debate in a confronting way. The interviews put the debate in a focused and realistic context. The book is important because it enables the euthanasia debate to proceed in the knowledge that acts of euthanasia and assisting others to die are not isolated occurrences. The interviews evidence the stark reality that, at least in the HIV/AIDS community, assisted death is available to those who seek it. The simple fact of widespread practice of assisted death and euthanasia is, in itself, a powerful response to those advocating continued operation of the current legal position in Australia which prohibits these practices, perhaps even to a greater extent than arguments based on personal autonomy and freedom of choice. The accounts are also a chilling reminder of the dangers of prohibition ('the euthanasia underground'). The interviewees describe a number of 'botched' suicide attempts, and the considerable adverse impact these experiences have on loved ones as well as the health care workers themselves. After reading such accounts, it is difficult for the reader to conclude that the existing situation should be allowed to continue unchecked. Finally, many of the accounts, particularly by palliative care nurses, personalise the complexity of end of life issues in the context of patients in extreme pain, suffering or distress. Arguments and philosophies based on the sanctity of life seem to lose poignancy when considered in the context of a mother's vigil at her child's bedside, that child being emaciated, in pain and wishing only for their life to end.

Magnusson states the purpose of his book is 'to expose the social practices, relationships, and networks that constitute "underground euthanasia"' and 'to demonstrate the complexity of the euthanasia issue, and in the process to capture some of the passion, pathos and bitter-sweetness of those bedside moments, as health professionals care for patients in the midst of pain, bodily decay and existential anguish'. The author has achieved both of these objectives, at least in relation to those suffering from AIDS related illnesses. The frank and sometimes startling disclosures of the interviewees certainly enlighten the reader about the ease with which information about assisted death can be obtained by AIDS patients, and the closely guarded network maintained by health workers in this area. Through the dilemmas and personal turmoil of many described by those interviewed, the complexity of the issues involved are starkly portrayed. Regardless of the personal views of the reader, after reading these accounts it would be difficult to conclude that there are any easy answers to the current situation.

Though it concerns a very difficult topic, Magnusson's book is easy to read. (In this writer's view, however, the readability could have been improved by the use of footnotes rather than a series of endnotes appearing at the end of the book.) The book is not written as a legal text, nor does it purport to be a detailed examination of all the legal issues concerning euthanasia or assisting a suicide or a blueprint for reform of the law in these areas. Rather, it is a book that would be of interest to all who wish to gain a

deeper understanding of the practice of euthanasia, especially those in the medical and legal professions. It informs us of practical imperatives that operate and which cannot be ignored when forming policy responses. Having said that, however, the work is limited in that it considers euthanasia almost entirely within the HIV/AIDS community. As Magnusson himself suggested, it would be interesting to conduct similar surveys in other end of life circumstances.

The strength of this book is that it focuses the euthanasia debate on where it needs to be - on the ground with the sick and dying, and with those who care for them. The philosophical issues about the sanctity of life versus the imperative of personal autonomy should not be considered in a vacuum. This is a balanced, considered and sensitive work. While gently concluding that legalising and regulating euthanasia practice is probably the appropriate way forward, the author is guarded in his recommendations and acutely aware of the challenges such a task presents. Justice Kirby eloquently commented on the value of Magnusson's work in the Foreword:

The special value of this book is that it contributes usefully to the debate about the response of our society and its laws to assisted death. It does so by going beyond verbal analysis, by which clever people express their opinions. It surveys life experiences of people involved in the 'euthanasia underground'. It is one thing to talk about great principles, whether found in holy texts or in modern statements of fundamental human rights. It is quite another to explore, in dialogue with doctors, nurses, patients, lovers and families, the largely hidden work in which patients in extremis are sometimes helped to die with dignity.