LETTERS

Commentary on Spriggs: genetically selected baby free of inherited predisposition to early onset Alzheimer’s disease

I note with interest the controversy regarding a baby born free of an inherited predisposition to early onset Alzheimer’s disease through the use of preimplantation genetic diagnosis (PGD). As the medical geneticist for the PGD programme for single gene disorders in Melbourne, Australia, I have seen many couples who have considered PGD for a wide range of genetic conditions. My observation is that many of them look to PGD for “milder” conditions and adult onset conditions for which they are not comfortable to have traditional prenatal diagnosis and termination of pregnancy.

An example of this is that in the last 11 years our unit has undertaken 13 prenatal diagnoses for Huntington’s disease from nine couples, whereas in the two years that we have been offering PGD we have had six requests for PGD for Huntington’s disease and three couples have already had IVF cycles.

I have a number of concerns with the argument that the woman should not have a child utilising PGD because she is predisposed to Alzheimer’s disease. Firstly, do the commentators believe that the couple should not have a child by natural means because of this fact? If so, for this case, what length of time should be gone to to prevent the woman becoming pregnant by natural means? If the commentators who make this argument agree that it is not appropriate to prevent couples where one is at risk of a genetic disorder from having children by natural means, then assisting them to have children not predisposed to a genetic disorder is in our view entirely ethically acceptable.

The concerns for the child of having a mother suffer from early onset Alzheimer’s disease are that they will not have a mother to bring them up and the impact this will have. While members of the woman’s family have developed disease in their 30s and 40s, this is by no means certain for the woman herself. The only other report of people with this mutation also had early onset Alzheimer’s disease but the numbers affected are very few, perhaps too few from which to draw a definitive conclusion about the exact age of onset for those with this mutation. For example the average of onset of the Val171Leu mutation is 57 years. This is a mutation involving the same amino acid (valine at position 171) and the substitution is for a chemically very similar amino acid (isoleucine compared to leucine). If the destiny of this particular woman is to develop Alzheimer’s disease in her mid 40s or beyond then her child will be an adult by the time she is severely affected. Even if we assume that onset of symptoms will be when the child is about 10 years old, the family are aware of this risk and can take steps to be prepared and put in place plans for this. Are couples with other sociological risk factors that put a child at risk of emotional deprivation prevented from utilising reproductive technology? In Australia at least, those who are from low income brackets or who use illicit drugs are not precluded from assisted reproductive technology, yet both these factors are associated with a number of poorer outcome measures for children.

Finally, PGD is a major undertaking for families. It is a protracted, expensive, and very stressful process and ultimately there is no guarantee that a child will be born through it. Many couples who consider utilising PGD do not go through with the process for these reasons and choose other reproductive options, including traditional prenatal diagnosis, and natural pregnancy with no intervention, or they decide against having children. Therefore families who undertake this process are generally highly motivated and, one intuitively feels that the resultant child is less likely to suffer social deprivation. This issue will only be resolved by long term follow up studies.

In conclusion, I believe that PGD is ideally suited to situations where families wish to avoid their child having a genetic disease, but where they feel uncomfortable about terminating pregnancies. This includes late onset conditions such as neurodegenerative diseases and familial cancer syndromes, as well early onset diseases that are considered relatively mild, such as deafness.

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References

Electronic submissions to the Journal of Medical Ethics

At the time of writing there appear to have been no electronic submissions to the Journal of Medical Ethics. It seems appropriate, therefore, to begin electronic correspondence with a consideration of some of the ethical implications of this new form of ethical dialogue.

I have posted this response to Kenneth Boyd’s editorial on Mrs Pretty and Ms B as this article may provoke debate far beyond the medical and ethical establishment. This issue may be of tremendous concern to patients or their carers who are presently suffering in circumstances similar to those described.

The electronic response forum of the BMJ has been in operation for over four years. An editorial in the BMJ on physician assisted suicide has attracted 125 responses at the time of writing. An important feature of electronic responses is that they can generate a lot of debate, is that the contributions often refer to each other. These responses range from the scholarly and meticulously argued to distressing accounts of suffering. As both an avid reader of rapid responses to the BMJ, and a physician, I consider both sorts of contributions to be valuable, but increasingly feel uncertain about what my written response to them should be when I wish to enter into dialogue with the author. I feel on sure ground when considering the scholarly submission that is clearly intended as a contribution to a peer reviewed journal, and have no qualms at drawing up a response to point out its weaknesses. Equally, as a family doctor, I hope that I am able to approach distressing accounts of suffering with a degree of empathy. It is sometimes the case, however, that submissions clearly showing distress also contain dubious argument that any peer review process would deal with severely. Where accounts of suffering alongside dubious arguments are posted from patients I personally feel squeamish about responding, finding myself caught between the roles of vituperative reviewer and empathic listener. As an editorial in the BMJ on the subject of electronic responses has noted: “We’ve begun to capture the opinions and experience of patients and publish just about anything that isn’t libellous or doesn’t breach patient confidentiality”. Inevitably, such a broad range of responses will produce many that deserve to be challenged. Merely to ignore dubious argument implies that such opinions are correct. Furthermore, it is astonishingly easy to post an electronic response, and the process contains no warning that opinions expressed may be severely challenged. We should consider what the rules of debate on this Journal of Medical Ethics web site should be.

To prevent any misunderstanding, I wish to state that this response does not result out of intense personal suffering, and that I am prepared for the most stringent peer review of its contents. Say anything in response, but please don’t ignore me.

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References
1 Boyd KM. Mrs Pretty and Ms B (editorial). J Med Ethics 2002;28:211–12
3 Doyal L, Doyal L. Why active euthanasia and physician assisted suicide should be legalised. BMJ 2001;323:979–80
Ethical Issues in Palliative Care—Reflections and Considerations


This book is a collection of essays by a variety of specialists with a particular interest in palliative care. It contains seven chapters by six different authors.

The first chapter Why is the study of ethics important? is by Patricia Webb, a lecturer in biomedical ethics, who explores the difference between care with a “set of rules” and care that depends on the relationship between patient, family, and colleagues. She tells us that studying ethics encourages logical reasoning and helps us to see the range of views on a particular issue. At the same time, it gives us an opportunity to consider the ethical issues and to give patients the best possible care.

The next chapter, How informed can you be? by David Jeffery, a consultant in palliative medicine, explains how to communicate with patients and their families. He shows us how to be skilful in sharing the reality of uncertainty with patients, family, and colleagues, and how to make realistic decisions.

In the chapter called Care versus cure by David Jeffery, a consultant in palliative medicine, we learn about the importance of care in palliative care. He discusses the importance of care in palliative care and the importance of care in the face of an ethical dilemma with no clear answer. He also points out that “patients have little power to influence the nature of care provision unless a determined effort is made to reduce their actual and perceived vulnerability”.

The chapter on Advocacy by Patricia Webb defines advocacy as “the role of one who has the ability and the expertise to negotiate on behalf of another”, and it is an interesting analysis of the power differences between patients and professionals.

The last chapter, How informed can consent be?, by Calliope Fardasides, a senior lecturer in medical ethics, shows us how to make informed decisions. He emphasises, however, that informed consent has its limits and that the patient may not be fully informed in all cases. He emphasises, however, that informed consent has its limits and that the patient may not be fully informed in all cases. He emphasises, however, that informed consent has its limits and that the patient may not be fully informed in all cases.
tact and express consent and the problems of coercion and "sufficient information".

In Euthanasia—slippery slope or mercy killing, Marny Prouse, a sociologist, director of nursing at a hospice, with a BA in law and now a risk and litigation manager, has written and published an essay on the euthanasia debate, and finally urges us "to research and practise our arguments and beliefs so that we can be comfortable and credible when moral ques-
tions about the end of life are discussed". The final chapter on Teaching ethics in the practice setting by Rachel Burman, a consultant in palliative medicine, emphasises that medical ethics involves many disciplines, including cultural, social, legal, theological, and philosophical, as well as medicine. The teaching of medical ethics is ideally done, she says, in a multidisciplinary group with sensitive and detailed discussion of real life ethical dilemmas, with both philosophers and clini-
cians facilitating. In the USA ethical commit-
tees are commonplace in hospitals, where there is often a resident ethicist on the staff to help with difficult cases, developing policies, and education. In the UK ethical committees have been largely restricted to looking at research protocols, but the development of clinical ethical committees to act as a forum and resource for managing difficult clinical dilemmas is accelerating.

Several of these chapters contain helpful clinical case histories, but the next edition of the book should contain a chapter, written by a clinical ethicist, with a collection of clinical cases and scenarios based on those discussed by ethical committees, together with a discussion of some of the key and dilemmas that they raised. This would demonstrate this powerful teaching method and would also provide some relevant practi-
cial material for teams and trusts that are try-
ning to set up their own ethical committees.

P Kaye

Life and Death in Healthcare Ethics: A Short Introduction


This is a compact, nicely written book that provides a reasonable alternative to the utilitarian orthodoxy that dominates contem-
porary bioethics. There is currently a dearth of bioethical literature presenting what might be called a more traditional approach to medi-
cine and health care. This contribution is a short and useful introduction to such an approach.

The book announces itself as being written with "both the general reader and students and professionals in medicine, nursing, law, philosophy and related areas in mind". Accordingly, it assumes no prior knowledge of ethics. It gives a neat introductory overview of some of the issues raised by reproduction, birth, death, and dying. The issues considered include euthanasia and withdrawal of treat-
ment, the persistent vegetative state, abortion, cloning, and in vitro fertilisation.

By the end of the book, with a real-life case, Watt captures the interest of the reader. The case is introduced and discussed dispassionately. It is then employed as a springboard for a general discussion of prin-
ciples often thought dry and difficult. Newcom-
ers to the study of ethics will be pleasantly surprised.

In the first chapter—for example, the Arthurean case is introduced as a context for dis-
cussing putative distinctions between killing and letting die, and intending and foreseeing; approaches to homicide suggested by compet-
ing ethical theories are also covered. In the second chapter, the Bland case is analysed and philosophical concepts such as that of "per-
sonhood" are discussed. Watt considers the notion of life as good in itself and raises ques-
tions about the social significance of feeding. The Cox case, in chapter 3, elicits a discussion on principles of double effect and questions of au-
tonomy. In this chapter, Watt introduces a concept he calls "lethal bodily invasion". Even if a Nazi doctor did not care whether the victims were subsequently resuscitated, on the doctor’s intention to invade their bodies in a way he knew would do them no good, but only lethal harm, would be enough to identify his course of action as grossly immoral. This is plausible enough in the con-
text Watt suggests. In order to test her prin-
ciples as outlined, however, Watt needs to exam-
ine other situations where the principle of double effect is one of the basic principles. The principle of double effect is often raised in the context of self defence, defence of a third party, and war. Clearly, the book is an analysis of the principle of double effect, and broad discussion of defensive action is well beyond its scope; however, it is profitable to analyse like cases where the principle of double effect is often summoned as a justification for deaths not intended as lethal, as in, for example, a mentally disordered man, or child for that matter, runs amok with a shotgun in a school, is a marks-
man not justified in shooting to maim? If the aggressor dies, is this lethal bodily invasion impermissible? If the man not be regarded as remiss if he failed to act to prevent the death of the schoolchild?

The principle suggested by Watt also ap-
pears to need qualification that even in cases where two patients will die and one is threaten-
ing the life of the other unless a doctor intervenes to save one, the doctor is required to do nothing and allow both to die. Such were the circumstances of the recent UK case of the conjoined twins, "Jodie" and "Mary". It is one thing to say that the doctor may decide not to inter-
vene—for example, on the grounds that he wants to respect the parents’ wishes: it is quite another to say that it is entirely impermissible to perform life-saving treat-
ment on one twin (even where the parents wish it), in the same way as it is impermissible for the Nazi doctor to use a patient as fodder for experimentation. In the conjoined twins’ case, there are relevant moral differences. The immediate aim, not merely the further end, of the doctor in performing the operation is to save the life of one of the children. The Nazi doctor, by contrast, has the saving of lives as, at best, his further end. It is worth remembering too that by Watt’s own account, sometimes omisions to act to save a patient can be justified in the same way as it is impermissible for the doctor refrain, on moral grounds, from treating either of the patients destined for certain imminent death is not moral reasoning gone awry.

Chapter 3 is followed by brief explorations of the controversial topics of abortion and embryo destruction. The final chapter looks at the question of moral disagreement and con-
cscientious objection. It is a reminder, if any be needed, of the practical nature of moral theory.

It is the book’s simplicity that leads me to believe that it will be read eagerly by students from a range of different disciplines. The layout and typographical style make the book particu-
larly accessible. There is a comprehensive index and bibliography. If I have a criticism, it is that the book could have been longer. However, for those who want a basic text to introduce them to life and death issues in bioethics, this is a most welcome contribution.

J Laing

Medical Ethics, 3rd edition


Medical Ethics, to quote the authors, is intended as a practical introduction to the ethical questions doctors and other health profession-
als meet. The book is divided into three main sections, Foundations, Clinical ethics and Medi-
cine and society; each section is further subdiv-
ided into topics dealt with in a single chapter.

The first section deals very well with the more contemporary philosophy rather than the more obvious contribution to the authors’ agenda, and does not lay too much stress on the well estab-
lished “four principles” (chs 1 and 2). I have rarely read such a seamless introduction to the underlying principles of medical ethics and how they would be treated in this section. The chas-
ters in this section deal with diverse cultures (ch 3) and the human body (ch 4). Of particu-
lar note here is the excellent treatment given to information, consent, confidentiality, and truth-telling; there is much to be gained here by the book’s intended audience. The chapter on the human body seems unusual in a book of this type, but is a well argued discussion of how the human body, both alive and dead, should be used as a teaching tool. This chapter also covers the ethics of postmortem examinations and biopsies both of which are in the public mind at present; this discussion is clear and full of “common sense” arguments. This book on the other hand is more immediately relevant as it is aimed at those who want a basic text to introduce them to the ethical issues they are likely to encounter. The New Zealand back-
ground of the original edition shows through most obviously in this chapter but this does not detract from the arguments put forward.

The “meat” of the book, however, is in the second section (142 pages out of a total of 297). The “standard” topics of genetics, prenatal problems, birth, organ transplantation, AIDS, euthanasia, and brain death are all dealt with well and clearly, especially transplantation. The general format of the chapters is to briefly dis-
cuss the medical problems and then to intro-
duce the ethical dimension. This ensures that a reader not familiar with a certain topic is reminded of the problems before entering into the ethical discussion. The chapters on genetics and ending human lives are particularly good in this respect. Two topics not commonly found in introductory texts are covered in this section, namely, psychiatry and the problems with aging and dementia. Both are discussed sensitively and with compassion and are welcome inclusions in a text of this type.

The final section covers research ethics, jus-
tice, law and “trying new things”. This rather broad area is dealt with excellently and the rather oddly named chapter on “Trying new and unusual things” is highly recommended reading for anyone wishing to introduce new treatments (medical or surgical).

Overall, the book is well organised and, while it is an introductory text, there are ample references to sustain the authors’ argu-
ments and for further reading. Case studies
The Use of Human Biobanks. Ethical, Social, Economical, and Legal Aspects


This booklet (freely accessible online at http://bioethics.uu.se/biobanks-report.html) documents a public hearing organised by a Swedish research project on the various social and ethical issues raised by the use of so-called biobanks—that is, large collections of human tissue samples. There is considerable interest among researchers, the biotech industry, and society at large in using biobanks for the continued investigation of genetic health factors that is now following the completed mapping of the human genome. Central issues are: the responsibility of biobanks or users of these to protect tissue donors in various ways; how these responsibilities should be balanced against business and research interests, as well as against the interests of people and against business and research interests, as well as against the interests of people and society in general in case of conflict and, not least, what procedures of informed consent (including the hard question of what constitutes informed consent) should be deemed as appropriate in the biobank setting. Although formulating these issues against the background of the actual scientific, legal, and political dynamics governing its (in)effectiveness. The author also covers extensive ground regarding the subject matter of ER

The Human Embryo Research Debates: Bioethics in the Vortex of Controversy


United States ethicist Ronald M Green approaches the issue of embryo research (ER) in the very accessible form of a “philosophical memoir” (xv). Reporting in detail from his experience of serving on several high level ethics advisory boards, focusing mostly on his membership of the National Institutes of Health’s (NIH) 1994 recombinant DNA advisory board, Green portrays both the strength and the limitations of institutionalised ethics, as well as the social and political dynamics governing its (in)effectiveness. The author also covers extensive ground regarding the subject matter of ER

The Encyclopedia of Ethical, Legal and Policy Issues in Biotechnology


This encyclopaedia is an important and comprehensive resource that is likely to be of value to a wide range of academic users for many years to come. It is particularly useful as a starting point for background research by bioethicists writing about topics in genetics and biotechnology. The collection takes a broad view, ranging from core topics such as genetic enhancement and the ethics of genetics research, to a series of sections that take the form of national reports on the political, ethical, and regulatory contexts covering genetically engineered organisms. One potential problem for any reference work of this kind is getting out of date, given the changing nature of biotechnological research. The articles in the encyclopaedia that we read were well written and clearly written in the main, looked likely to be relevant for a while to come. The first thing that strikes you about the two volumes of this encyclopaedia is that they are very well made, attractive, solidly bound books. Their formatting is reinforced by first use of the title and the headings. A great deal of care has gone into making this reference work accessible and a pleasure to use. Two very minor additions that would have increased this ease of use would have been to add page numbers to the list of headings and a contents page to the second volume. Nevertheless as a whole the collection was extremely easy to navigate.

Overall, the editors have assembled an impressive cast, with many of the American names that you would expect to be involved in such a project. This does bring us to our first minor grumble: there are about a hundred contributors to this volume but only three are from the United Kingdom. This absence cannot be due to a lack of UK expertise and it is slightly disappointing that there is no contribution from writers based in the UK such as Ruth Chadwick, John Harris, or Soren Holm. This does raise the question of how attractive this volume is likely to be to the readers who are not in North America. In addition to the majority of authors, being from the USA, much of the public policy and legal discussion in the volumes is US centred. It is hard to see how this could have been avoided, given the authors, however, it does mean that the researcher using this text will need to be careful to ensure that the normalised and exemplary developments in the rest of the world.

Given that these two volumes cost £370 it’s unlikely that any but the most enthusiastic and wealthy individual will be able to buy the encyclopaedia. This is primarily a collection for libraries.
The Androgen Insensitivity Syndrome Support Group (AISSG)

The Androgen Insensitivity Syndrome Support Group (AISSG) http://www.medhelp.org/ www/a is a consortium of worldwide support groups, originating in the UK, providing information and support to adults and families affected by some conditions affecting the development of the reproductive system. These are conditions that have been subject to considerable secrecy and paternalism in the past, and AISSG promotes full disclosure of diagnostic information with accompanying psychological support. It also encourages recent moves to evaluate the efficacy of genital reconstruction surgery and supports the notion of autonomy and informed consent.

The conditions supported included AIS—androgen insensitivity syndrome (old name testicular feminization syndrome or testicular feminisation syndrome)—and similar conditions, for example, XY gonadal dysgenesis (Swyer's syndrome), 5-alpha reductase deficiency, ledig cell hypoplasia, Mayer Rokitansky Kuster Hauser (MRKH) syndrome, Mullerian dysgenesis/aplasia, and vaginal atresia.

9th Conference of the ABA: “Virtue and Vice in Bioethics”

You are invited to the 9th Conference of the ABA: “Virtue and Vice in Bioethics” on the 3–6 July 2003. The venue is Queenstown, New Zealand. Confirmed invited speakers: Art Frank, Carl Elliot, and Annette Baier. Further information: Pat Johnston, Dunedin Conference Management Services, New Zealand (tel: +64 3 477 1377; fax: +64 3 477 2720; email: pat@dcms.co.nz).

European Integration: Philosophy and Ethics of Health Care

The XVIIth international congress of the European Society for Philosophy of Medicine and Healthcare will be held from August 21–23 2003 in Vilnius, Lithuania. Its theme is European Integration—Philosophy and Ethics of Health Care. Further information: Professor Dr Henk ten Have, secretariat ESPMII, Department of Ethics, Philosophy and History of Medicine, University Medical Center, PO Box 9101, 6500 HB Nijmegen, the Netherlands (fax: +31 (0)24 340254; email: h.tenhave@efg.kun.nl).

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