Bearing witness

As an editor of a specialist journal like the Journal of Medical Ethics, you sometimes experience a certain ambivalence when authors submit a very good and very important paper, because you feel that the issues raised in the paper ought to get far greater public exposure than your journal is likely to provide. In the present issue, we publish one of those papers. The paper by Deborah Zion and coauthors describe and analyse the ethical problems faced by nurses who worked in the Australian asylum seeker detention system (see page 546). It shows how a system that deprives asylum seekers of most of their rights may also deprive healthcare professionals of the possibility to work in a professional and ethical manner. The description of the conditions under which asylum seekers were detained and nurses expected to work are harrowing and exposes the detention system as rotten and unethical to the core. But the paper also shows how nurses were nevertheless able to resist and to bear witness. In their daily interactions with asylum seekers, they could subvert the inhuman system by bearing witness to the common humanity that bound them together with their clients, and in the public sphere they could bear witness to the inhumanity of the system. These acts of resistance were difficult and sometimes performed at significant personal cost, but they were nevertheless seen by the nurses involved as part of their ethical duty.

The TGN1412 trial: how good were the participant materials?

In 2006, six healthy volunteers experienced very serious adverse events in the phase 1 trial of the antibody TGN1412. They had all consented to participate in the trial after receiving written and oral information, but how good was that information? Knapp et al tested the original patient information sheet on members of the public and found that: “... it performed poorly (see page 573).” Members of the public found it hard to find information about the trial, including its nature and purpose, consent, trial procedures and information about the tested medicine. When information was found, it was not always understood.” This finding is not surprising. It is a fairly consistent judgement in the large literature on information sheets that they are difficult to read and understand. The authors of the present study do, however, take the literature forward in two ways: they show that the document can be rewritten and redesigned in a way that retains its meaning but makes it much more reader-friendly and understandable; and they show that mere testing for readability is not sufficient to evaluate the actual performance of an information sheet.

Facebook ethics

The Journal of Medical Ethics has a Facebook group, as have many other journals (and if you are not already a member of our group, go there now and become one!). But social networking sites such as Facebook may create new ethical challenges for healthcare professionals. In the paper “Medical professionalism in the age of online social networking” some of these challenges are described and analysed (see page 584). Should doctors become “friends” with their patients on Facebook? What kind of personal information should doctors put in their profile? And should doctors use information they gain about patients on social networking sites in future clinical encounters (eg, information about smoking or other unhealthy habits)?

The authors propose four guidelines for doctors participating in social networking. Most of these seem unexceptional, but some seem very conservative. Why should a doctor who only uses social networking on the internet to network with people who are already friends or acquaintances in “real life” for instance “... populate their site only with professional information...”. The amount of searchable information that is already available about each of us using specialised search engines such as pipl.com is already so vast that limited self-disclosure on Facebook is unlikely to add much to it.

Would you sell a kidney?

A regulated market in human organs has been proposed as a possible solution to the problem that the number of organs available for transplantation is lower than the number of organs needed to provide transplants for everyone on the waiting list. But would a market in kidneys increase the supply of kidneys? The paper by Annette Rid and colleagues attempts to provide a partial answer to this question by investigating under what conditions Swiss medical students would be willing to sell a kidney (see page 558). There are many interesting and thought-provoking findings in this study, but let me just mention two to whet your appetite. The first is that there is no association between considering selling a kidney in a regulated market and a person’s view concerning whether such a market should be legalised. And the second that most who are willing to sell are only willing to sell if it is either “necessary to overcome a particularly difficult financial situation” or if they can thereby achieve a “secure future”.

Levelling down

Egalitarian theories of justice are often claimed to be open to the so-called “levelling down” objection, ie, the objection that one way of achieving greater equality is to take something away from those who are best off without improving the position of those who are worse off. Norheim argues that the levelling down objection can be dealt with by acknowledging a pluralist approach to the distribution of well-being, an approach that values both fairness and goodness (see page 565). He furthermore provides a set of examples that suggest that a possible measure of equality in health, Wagstaff’s Achievement Index, is not sensitive to levelling down while still being sensitive to inequalities in health. If this is true, the force of the levelling down objection may be dissipated in relation to equality in health.