One of the most important advances in acute care medicine over the last thirty years has been the development of organ transplantation. In many instances, such as end-stage liver and heart disease, organ transplantation saves lives. In others, such as kidney disease, organ transplantation frees patients from dependence on expensive medical technology and allows them to resume an almost normal mode of existence. From a humane perspective, this makes organ transplantation very attractive.

The benefits of organ transplantation are not confined to patients. Kidney transplantation is economically more cost-effective than continued renal dialysis of patients; and as transplantation techniques become more sophisticated for other organs, similar cost savings will be realized in other areas as well. Therefore, as health-care resources are increasingly being diminished, transplantation emerges as an appealing health-care modality.

However, organ transplantation depends on the availability of organs. All countries are experiencing an acute shortage of human organs for transplantation. At any given time and in any jurisdiction, there are hundreds of people waiting for transplants. Quite literally, they are waiting for a new lease on life. That is why transplant societies in all countries are doing their best to raise organ donor awareness so that more people will donate their organs; and why medical establishments and surgical teams are working to improve their techniques of organ recovery and transplantation. When the lack of a suitable organ may mean death, every organ counts and no organ may be wasted.

The responses to this organ shortage have been varied. Some countries treat human organs and bodies as commodities that belong to the individual person and that may be sold by these individuals for a valuable consideration. This lets economics decide who will have access to transplantable organs and entails that market forces determine how organ shortages are dealt with. If the shortage is severe – so goes the theory – prices for organs will go up, sellers will appear in the market-place and the shortage will thus be alleviated.

Most countries have rejected this position for several reasons. First, they believe that people have such a close association with their bodies that to consider bodies and organs as property is tantamount to considering the people themselves as chattels. Hence they maintain that neither bodies nor body parts may be bought or sold. Second, they believe that if the ownership (and hence sale) of bodies or body parts were to be allowed, this would lead to a state of affairs where the rich would take advantage of the poor by offering such high prices for human organs that the poor would be unable to resist the enticement. The
poor would therefore become the walking organ banks of the well-to-do. While this might alleviate the organ shortage in the case of affluent persons in need of organs, it would do nothing about the transplantation needs and the availability of organs for the poor.

In contrast, therefore, most countries have adopted the position that, while there is no ownership in human bodies, everyone has a right to decide what shall happen with her or his own body and that this right extends even beyond death. Beyond this, however, there is no general agreement. Some countries have instituted presumed consent legislation. That is to say, they have passed laws which mandate that, unless people have explicitly stipulated that they do not wish to be organ donors, their organs will be retrieved once they are dead. Other countries view organ donation as a supererogatory act that cannot reasonably be expected of all persons. Consequently they have passed laws which state that specific agreement to donation is a sine qua non for organ retrieval, and that this agreement must come either from the potential donor during her or his lifetime or, in the case of persons who have not made a decision in this matter, from those who are legally in possession of the body after the person is dead. These usually are the next of kin.

Unquestionably, the voluntary approach to organ donation can easily exacerbate the shortage of transplantable organs simply because potential donors (or their relatives) may be reluctant to agree to donation. This reluctance may be grounded in religious precepts which construe the removal of an organ as the sacrilegious mutilation of the body and hence consider it anathema. Alternatively, the refusal may be grounded in a psychological perspective that finds organ retrieval personally offensive on aesthetic grounds. Finally, the refusal to donate may be based on a mere misunderstanding about the process of retrieval itself and the nature of death. Specifically, it may be based on the assumption that death occurs only when there is a complete and irremediable cardiovascular collapse of the body which cannot be alleviated even by mechanical ventilation. This leads to the refusal to allow organ retrieval until after all such attempts have proved unsuccessful – which effectively guarantees that the relevant organs have also deteriorated beyond the point of usefulness for transplantation.

A further contribution to the shortage of organs lies in the fact that many potential donors are simply unaware of the option of donation. Hence organs that otherwise might well be donated are never retrieved.

There is little that can be done about a refusal to donate which finds its basis in religious conviction, short of changing the tenets of the relevant religion or prohibiting adherence to the religion itself. Neither of these is morally acceptable. With due alteration of details, similar considerations apply to refusals to donate that are based on personal aesthetics.

On the other hand, organ shortages that are grounded in misinformation or in ignorance of the option of donation can be alleviated by properly focused and conducted educational campaigns. Physicians can be encouraged to raise the subject of donation with their patients, to educate them about the benefits of donation and to explain to them the nature of death. Further, transplant societies can maximize the chance of retrieving donated organs by establishing organ donor registers which list everyone who has agreed to being a donor. On the death of such a person, it would be known immediately whether that person had agreed to donation.

Furthermore, it has been suggested that all jurisdictions adopt presumed consent legislation. In this way, it is hoped, the supply of organs will be increased because refusal to donate would have to be explicitly expressed.

However, there is a readily available supply of organs which does not require the establishment of registers or changes in the current laws. Access to this supply does not require a change in anything – except in the way in which the various transplant societies work.

More precisely, in many countries that have consent legislation, the law states that the consent of a competent person is “full” and “binding” authority for the removal of that person’s organs after death for the purposes of transplantation. In legal terms, the word “full” means that if someone has given consent, then this consent is sufficient and no one else needs to be asked for permission, while the term “binding” means that others may not overrule the consent of the donor and substitute their own wishes. Such consent is usually signified by an organ donor card or an organ donor sticker on the person’s driver’s licence.
Almost without exception, the organ retrieval protocols of most transplant societies are out of step with these provisions. Almost invariably, they state that the consent of the next of kin is required for organ retrieval even when there is a donor card or sticker. They further state that if the next of kin refuse the donation, the organs will not be retrieved.

In countries which have consent legislation that recognizes the individual’s right to donate, these protocols clearly violate the law. In the great scheme of things, that may not be too important. However, what is important is that, because of these protocols, many organs that could be retrieved and used to save lives are never recovered. In other words, because of these protocols, the current organ shortage is greater than it needs to be, people are on waiting lists when they do not have to be, and people are dying while waiting for a suitable organ.

These are preventable deaths. They are therefore tragic. They are all the more tragic because they have ramifications far beyond the immediate sphere of the donor and the prospective recipient: they have implications for the availability of health care in general. Every organ that is not retrieved represents increased health-care costs for society. Health-care resources are finite; what is given to the one is taken away from the other. Therefore the impact of this non-retrieval affects not only the person who could have received the organ but everyone in the health-care system as a whole.

These protocols also have serious ethical implications for the ethics of informed consent. What the transplant societies are in effect saying with their guidelines is that the informed donor consent will not be considered binding if the donor is no longer capable of enforcing her or his wishes. Such an attitude sends the message that organ donation really doesn’t mean anything: that the wishes of others really carry the day. If that practice were to be adopted in other areas of health care, informed consent would become meaningless. In fact, it would become a farce. It is surprising that, under the circumstances, anyone bothers to donate organs at all!

The transplant societies have argued that to retrieve organs against the wishes of the next of kin runs the danger of being perceived as ghouls, and that the negative publicity that would surround such actions might well result in a drop in organ donation. That is why they have proposed the establishment of a donor register, and that the law be changed in all jurisdictions in favour of presumed consent.

Unquestionably, the establishment of organ donor registers would be useful. So would the proposed change in legislation. Unfortunately, however, neither of these comes to grips with the real issue; and more important, neither of them would change the situation.

A register is useful only if the donors who are registered actually have their organs retrieved upon death. There is nothing inherent in a register to ensure that this would take place.

As to the proposed consent legislation, it would still leave the possibility that the next of kin might say no to organ retrieval even though the donor him- or herself had not said no. Therefore unless, under presumed consent legislation, the next of kin were not asked for their consent, the number of organ retrievals would not go up. The same number of next of kin who now refuse consent would also refuse their consent under the new legislation. The only way to avoid this would be not to ask the next of kin (or to ignore what they might say) and simply go on the assumption that, if the person had not wanted her or his organs retrieved, he or she would have said so. Therefore these proposed laws would work only if the transplant societies acted the way they are supposed to act even under the current laws. There is considerable justification for doubting that this would be the case.

The crux of the matter is really this: do people have the right to decide what shall be done with their body after they are dead? In particular, do they have the right to donate their organs in order to save lives? The answer may vary from society to society. However, once such a right is recognized, the ethics of informed consent entails that the donor’s decision should not be overruled – or ignored – simply because others are uncomfortable with that decision. Not only does that violate the autonomous decision of the donor, it also costs lives. If others – e.g., the next of kin – are uncomfortable with the donor’s decision, what is called for is not a refusal to follow the donor’s last bequest but appropriate education and counselling in the ethics of donation and informed consent.
Always following the wishes of organ donors would not do away with the current shortage of organs. However, this shortage would not be so great if the donated organs were in fact retrieved, if the wishes of donors were followed – and if the ethics of informed consent were taken seriously. When every organ is a life, can one be less than ethical?

Note

1 Personal communication with various transplant organizations in Canada, US and Europe.