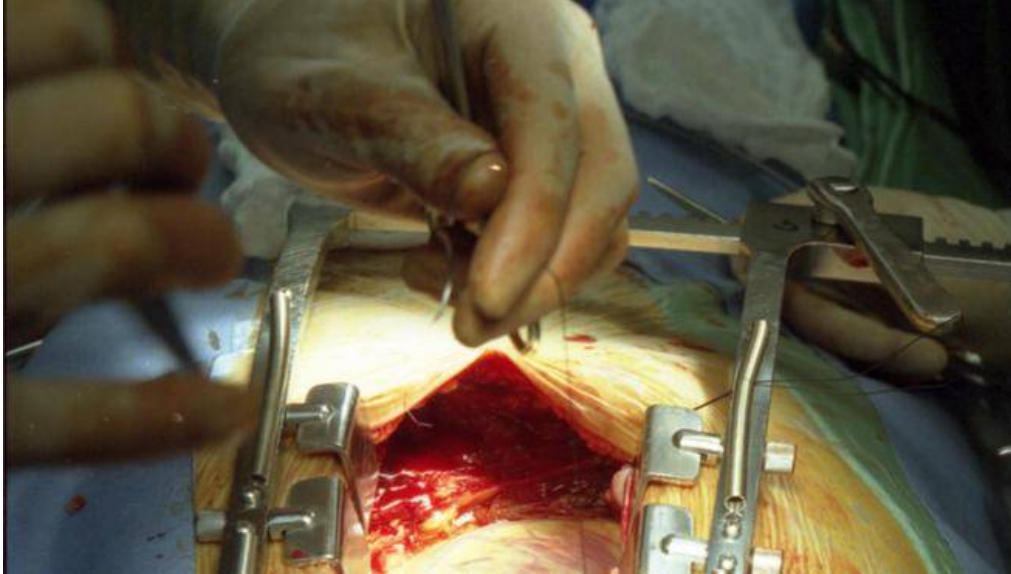


ORGAN DONATION: Presumed consent highly presumptuous

BY JACQUELYN SHAW

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A heart transplant is performed in Halifax. (TIM KROCHAK / Staff)

Stephen McNeil's government is proposing a "presumed consent" organ donor regimen for Nova Scotia, to address "low" donor rates; supporters urge a Nova Scotian "conversation."

Ironically, from one viewpoint, "conversation" is the problem. Obtaining consent for organ donation should involve an individualized conversation with donors, yet nothing like this occurs. A presumed consent regimen may only worsen things.

Before any medical procedure performed in Canada — except emergency procedures to save that individual's life — informed consent to the procedure's risks and benefits must be obtained or the procedure is illegal.

Organ donation should be no different. Under the current donor system, problematically, no real information is provided in obtaining donors' consent (during driver's licence renewal). Some donors may feel unclear and ill-at-ease about the circumstances surrounding organ harvest; others may fear the worst of this information "black hole" and simply refuse to donate.

It is no answer that relevant information is available from organ procurement organizations (OPOs) like Trillium. These bodies exist to encourage donation, so they are ill-placed to inform people of risks.

Notably, most OPO information focuses on society's regard for donor generosity and the comfort provided to families affected by a tragic death. Yet risks do exist, including premature death declaration, whose frequency is unclear.

Adopting presumed consent in Nova Scotia would worsen a bad situation. In a democratic nation, if most people claim theoretical support for a practice, but the actions of the majority clearly do not, then it seems unreasonable to conclude that the necessary social licence exists for legislation requiring that practice.

While such legislation would be generally unfair, it may be especially unfair to certain groups — e.g. immigrants, or some with disabilities — who are less able to "opt out."

I can think of no better way to send the message that a government does not care about its citizens' actual values than by riding roughshod over everyone's informed consent needs through presumed consent.

At a minimum, research is needed to explore why many do not donate, rather than simply appealing to emotion by claiming that non-donors are ignorant, lazy or selfish (thus requiring correction).

Other factors may be at work. Health-care workers, through training and experience, are more aware than the general public of health-care realities (good and bad), getting around the donor information “black hole.” They also receive more frequent reminders of donations urgency.

If public ignorance, laziness or lack of altruism is the problem, then health-care donation rates should markedly outpace those of the general public. Yet Canadian surveys in the mid-2000s showed otherwise.

Despite over 90 per cent of the public and health-care staff claiming theoretical support for organ donation, each displayed much lower donor rates of around 60 per cent (health-care workers’ rates were just slightly higher). This might be significant.

A relevant second issue is that death is not always a simple diagnosis. In 2003, a government body, mandated to increase organ supplies and staffed with transplant experts, created major changes in Canadian brain-death determination.

Through voluntary medical guidelines, it changed the definition of brain death from “whole-brain death” (used since 1968) to the easier-to-meet U.K. “brainstem death” standard.

Other serious safety problems surfaced with these guidelines, appearing to risk brain-death misdiagnosis, possibly borne out in an Albert baby’s misdiagnosis in 2009.

Because life support or organs may be removed after death declaration, misdiagnosis detection is difficult. The guidelines were adopted sporadically throughout Canada, including in all of the major Maritime transplant hospitals, but not everywhere.

Thus, a brain-damaged patient may be diagnosed “dead” in one Canadian region (e.g., Nova Scotia), but “alive” elsewhere. Although in 2008, the Canadian government withdrew the group’s mandate, transferring it to Canadian Blood Services, these guidelines remain in effect.

Due to public unawareness, these guidelines may have little affected donation. Yet more importantly, are we serious about assuring dono (and non-donor) safety?

If we are — as we should be — then we should urgently replace the guidelines with safer ones drawn up by a more diverse body, committed first to the safety of dying patients, and only then to transplant needs.

Legislation ensures separation between individual physicians performing death declaration and organ harvesting, but this is useless if we do not ensure the same thing collectively, of groups of physicians designing the guidelines.

At present, an unwitting conflict of interest is perpetuated each time a physician employs these 2003 guidelines, as their problematic content reveals. This unacceptable situation must not continue.

OPOs might encourage presumed consent as an ideal solution. Yet this ignores the reasons for public resistance to organ donation. It also exacerbates problems with the 2003 brain-death guidelines.

I sympathize with those needing organs, having known several who received, await, or died awaiting a transplant. It is an awful situation, and no one is immune. But I strongly believe that presumed consent is not the answer we need.

For further information, see Dalhousie University’s Novel Tech Ethics website, at ‘Brain death’: noveltechethics.ca/what-we-do/neuroethic and the ‘Impact Ethics’ blog at: [impactethics.ca/2014 / 04 / 04/ needed-better-guidelines-for-defining-death/](http://impactethics.ca/2014/04/04/needed-better-guidelines-for-defining-death/)

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Caribbee • 24 days ago

I am a fair man and I give or loan things whenever I can. But if you want something of mine you must ask first. Don't ever presume my body parts are free for the taking.

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disqus_dloXpZL7A6 • 24 days ago

Presumed consent is wrong! The business community is not allowed to use this unethical practise why should govt. For instance if a company sends you a proposal for those encyclopedias you don't want and says if you do not contact us within 10 days we will presume you said yes and ship them and bill you for them.....this is wrong.

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LookUpAlways • 24 days ago

This is the most reasonable piece I have read on the subject. Presumed consent is inappropriate at best, and unethical or illegal at worst.

7 ^ | v • Share



gman • 24 days ago

I have checked the box for organ donation on my drivers license. If they are able to find anything of use in this worn out carcass they are welcome to it but only because I gave prior consent.

4 ^ | v • Share



JGHali • 23 days ago

Having been involved in ICU cases where brain death has been declared, I think most of the concerns expressed in this article are unfounded. A very stringent process is used to confirm both absence of brain stem reflexes and autonomic respiratory drive. I disagree that these are necessarily difficult diagnoses to make or that there are any relevant conflicts of interest - the transplant team remains completely separated from the physicians making the declaration of brain death.

In practice, consent is given by family members based on their understanding of what the patient would want. I'm not actually sure that a "presumed consent" regime would change much as it's unlikely that harvesting would occur without the family's notification and, more likely, an explicit meeting to determine whether they want to go forward with it.

This is of course a complete non-issue for cadaveric donations post-cardiac death. I'm not sure why the author would ignore that situation, as it is far more relevant to the presumed consent model than anything she writes about here.

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