



L'Arche Canada

L'Arche Canada offers this "thought sheet" as a contribution to the public conversation about values and the shaping of the social ethos in which we live. Our perspective comes from two broad sources: (1) from thirty-five years of living together in community as a diverse group of people, differently abled and from various cultural, ethnic and religious backgrounds; and (2) from contemporary thinkers who are open, fresh and responsive to the human spirit and are reflecting deeply on the individual and society today.

The vision and confidence to create a healthy Canadian society lies in the nexus where humanistic thinking and spirituality cross-fertilize. Indeed, today the best spiritual thinking engages contemporary culture with a view to the good of human society and the best humanistic thinking integrates spiritual values. We believe it is possible to live consciously in the gap between an ideal society and everyday reality and to make choices that contribute to the closing of that gap. It is a hopeful view, based on human and spiritual values embodied in daily life.

A Human Future

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Perfection? Human Values in the Balance

An interview with Margaret A. Somerville



Margaret A. Somerville, AM, FRSC, A.U.A. (pharm.), LL.B. (hons), D.C.L., LL.D. (hons. caus.) With a pharmacy background from Australia, in the '70s Margaret Somerville did a Doctorate in Law on the ethics of medical research and, as she describes it, fell in love with this field. She was recently chosen by UNESCO as the first winner of the Avicenna prize for Ethics in Science. She is the founding director of the McGill Centre for Medicine, Ethics and Law, and holds professorships in both the Faculty of Law and the Faculty of Medicine at McGill University, Montreal.

Leading Canadian bio-ethicist Margaret Somerville is an incisive critical thinker and a passionate spokesperson who raises important questions about the nature of human life, the human yearning for perfection and the trajectory of scientific research today. In May 2004, she addressed Canadian L'Arche leaders. Her lecture, "Technoscience and Perfectionism: Eliminating People with Disabilities," and a telephone interview are the sources for this issue of A Human Future. Beth Porter, ed.

A Human Future is a free e-quarterly. We invite you to read back issues and to subscribe at: www.larchecanfoundation.org.

BP: What is your work today, and in what directions is it taking your thinking?

MS: I have three current projects: ethics and people with disabilities (for a Rights Manual); the ethics of withdrawing artificial hydration and nutrition from irreversibly comatose people; and respect for life in the context of the interventions made possible by the new repro-genetic (reproductive and genetic) technologies.

In all my work I am struck by the enormous divergence in fundamental values that is expressed

in the way we view human perfection. I have identified three worldviews. First, there are those who seek what

"I am struck by the enormous divergence in fundamental values as expressed in the way we view human perfection."



Michael J. Sandel



It is commonly said that genetic enhancements undermine our humanity by threatening our capacity to act freely, to succeed by our own effort... It is one thing to hit 70 home runs as the result of disciplined training and effort, and something less to hit them with the help of steroids or genetically enhanced muscles....

Though there is much to be said for this argument, I do not think the main problem with enhancement and genetic engineering is that they undermine effort and erode human agency. The deeper danger is that they represent a kind of hyperagency – a Promethean aspiration to remake nature, including human nature, to serve our purposes and satisfy our desires. The problem is not the drift to mechanism but the drive to mastery. And what the drive to mastery misses and may even destroy is an appreciation of the gifted character of human powers and achievements.... Appreciating the gifted quality of life constrains the Promethean project.... It is in part a religious sensibility. But its resonance reaches beyond religion.

From: "The Case Against Perfection: What's wrong with designer children, bionic athletes, and genetic engineering," by Michael J. Sandel, (Professor of Government at Harvard University) in *The Atlantic*, April 2004.

they see as human perfection, especially physically and with respect to cognitive mental functioning.

They believe there should be few if any limits on the use of the new technoscience. One aspect of their (re)search is the "de-selection" – a euphemistic distortion of the word elimination – of those whom they view as imperfect. They see science as eventually making us perfect – even immortal.

The polar opposite view is held by those who reject the new science as antithetical to their religious beliefs. They often practice a literal reading of religious texts and see all humans as deeply flawed. To even imagine we could be perfect would be sinful.

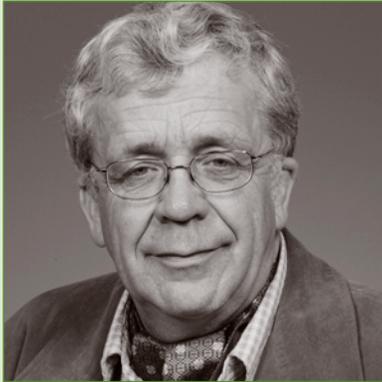
Then, there are those who accept life in all its diversity and usually do not regard any of us as perfect no matter how close we might come to contemporary ideals, or alternatively, see each of us as perfect in our own unique way – see beauty and mystery in all life. They believe there should be limits on how we use the new technoscience. They see the search for perfection as unethical and perilous to certain individuals and to society.

I know I'm preaching to the converted in saying to you in L'Arche that we should strive to ensure the third view prevails, but it is very important to understand what is necessary if there is to be a reasonable chance for that outcome. The arguments and forces on the side of the first view are powerful, can be attractive and, often, can be presented in a way that confuses (sometimes deliberately) our moral intuitions and reasoning. The second view is radically opposed to the first view, but, paradoxically, in being so could promote the latter. Moreover, it's not just a matter of making one decision for or against each view or dealing with one situation in which that will be decided. There are multiple, not always obvious situations in which decisions promoting one or other worldview are being taken. The final outcome in terms of our societal values will be decided by the cumulative effect of these decisions.

BP: What are the challenges to public involvement in this area?

MS: One big challenge is to discern what a 21st century pub-

Jacques Dufresne



Today the important and civilizing idea of “perfection” is reduced to “performance.” Perfection is understood as a perfect functioning, analogous to the performance of a well-working machine. In The Atlantic April 2004 article “The Case Against Perfection,” the author unmaskes the ideal of biological perfection in the name of which the most imprudent genetic manipulations are being justified. The pursuit of this idea of perfection seems to be the principal cause of doping in sports competitions. In a similar vein, Huxley’s Brave New World presents a “perfect” world order. There is truth in Lord Acton’s comment that the surest way to create hell on earth is to try to create heaven!

In its authentic sense, Perfection presupposes a contradiction: We are finite beings in a finite world aspiring to the infinite. But in rare moments we glimpse the perfect. When this happens it seems to us something miraculous, something from above that manifests a fragile unity – perhaps in the form of a beautiful scene in nature, a work of art, or a person whose words and actions radiate light.

Free translation from *L’Encyclopédie de L’Agora*. Jacques Dufresne, editor, is a well-known Québec philosopher, social and political commentator and writer. Encyclopedia: agora.qc.ca/mot.nsf, Magazine: agora.qc.ca/mag.html



lic square is. When communities were limited in size, people could talk together. Today the internet opens enormous possibilities, but the problem is how to ensure that peoples’ voices are heard. Ethics emerges from free and open conversation and debate. I find it concerning when the media promote a partisan agenda and other opinions are dismissed or people are pigeon-holed because of one opinion they hold.

I would say, above all, avoid becoming cynical, and keep hoping. Hope is the oxygen of the human spirit – essentially a sense of connection to the future. Then, remember that to be the ethical voice crying in the wilderness need not be futile. Systems research shows that if a small critical mass that represents a certain point of view is maintained, its voice will eventually become stronger and it will take its place in the public square. But if this critical mass is lost, that voice is gone forever. The same principle holds true in ecosystems. We need courageous, creative people. I think L’Arche is an example – the values it encapsulates in the context of sharing life with people with developmental disabilities are enormously important.

BP: Is religion important for ethics?

MS: Yes. I don’t think it matters what religion one is. It’s a spirituality that’s important – not in the traditional sense of a religion but as an attitude – knowing that we cannot see or know all. It has to do with a kind of humility before the universe. My guess is we will find genes for spirituality that have to be activated at a young age during a critical window, and if they are not, the person never develops a capacity for spirituality. Windows exist for activating other similar traits, such as nurturing. I think it’s wrong to say, Let children grow up without religion and they can choose later.

BP: Would you please say a little more about the way religion or spirituality impacts bio-ethical decisions.

MS: Humans have always focused on the two great events of human life, birth and death, to form their most important personal and societal values.

In the context of end-of-life decision-making, recently the Pope put the moral cat among the ethical pigeons. He stated “that removal of nutrition and hydration from patients in a vegetative state [or irreversible coma, to use a less de-humanizing term] who are not otherwise dying is gravely immoral”. It is common practice in North American hospitals to withdraw such treatment. In ethics, medical treatment may be withheld provided that is justified, but basic care must always be provided except if expressly refused by the person. Central to the Pope’s stance on artificial hydration and nutrition is that “the administration of food and water” is always basic care and not medical treatment. With respect, I disagree. While food and water in general are basic care, I propose that artificial hydration and nutrition are not. They are medical treatment. The Pope is correct that the intrinsic value and personal dignity of each human being does not change with the loss of consciousness. Nevertheless, allowing a person to die from withdrawal of treatment can be wrongful or rightful, depending upon the circumstances of each case and the justification for the withdrawal.

A Human Future is edited by Beth Porter.



The L'Arche movement was founded by Jean Vanier, in France in 1964. Today there are 121 communities of L'Arche on five continents, 26 in Canada. In L'Arche, people with developmental disabilities and those who come to assist them share life together.

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L'Arche Canada Foundation, 10265 Yonge Street,
Richmond Hill, ON L4C 4Y7, Tel: 905-770-7696, Fax: 905-884-4819
Email: office@larchecanfoundation.org
Web-site: www.larchecanfoundation.org

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BENEFITING FROM A MEDICAL TREATMENT



Photo: Wendy Lywood

Wherever he is, **Michael Barrett** (left) brings his gift of love for life, for music and fun. Though Michael has cerebral palsy and cannot talk, he expresses himself and answers simple questions with his eyes. Michael receives his daily nourishment through a gastric tube inserted into his abdomen. Before he had this minor surgery, he had difficulty swallowing and was slowly losing weight and becoming unwell. Michael has many friends, and has deeply touched and transformed the lives of numerous young assistants who have lived with him in L'Arche.

FOR YOUR INTEREST

- By Margaret Somerville:
The Ethical Canary: Science, Society and the Human Spirit, 2000. Viking/Penguin (in Canada and Australia); McGill-Queen's University Press (USA and Europe). *Death Talk: The Case Against Euthanasia and Physician-Assisted Suicide*, McGill University Press, 2001. “Technoscience and Perfectionism: Annihilating People with Disabilities,” (Address to L'Arche leaders), 2004: www.larchecanada.org/resources/
- Jacques Dufresne: *Après L'Homme... Le Cyborg?* Quebec: MultiMondes, 1999.
- Canadian Biotechnology Advisory Committee (CBAC): cbac-cccb.ca/epic/internet/incbac-cccb.nsf/en/Home
- Biologics and Genetics Therapies Directorate, Health Canada: www.hc-sc.gc.ca/hpfb-dgpsa/bgtd-dpbtg/awsreport_e.html
Much other information can be accessed through this site.
- Government of Canada Assisted Human Reproduction Act (2004): laws.justice.gc.ca/en/a-13.4/2294.html