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Expression

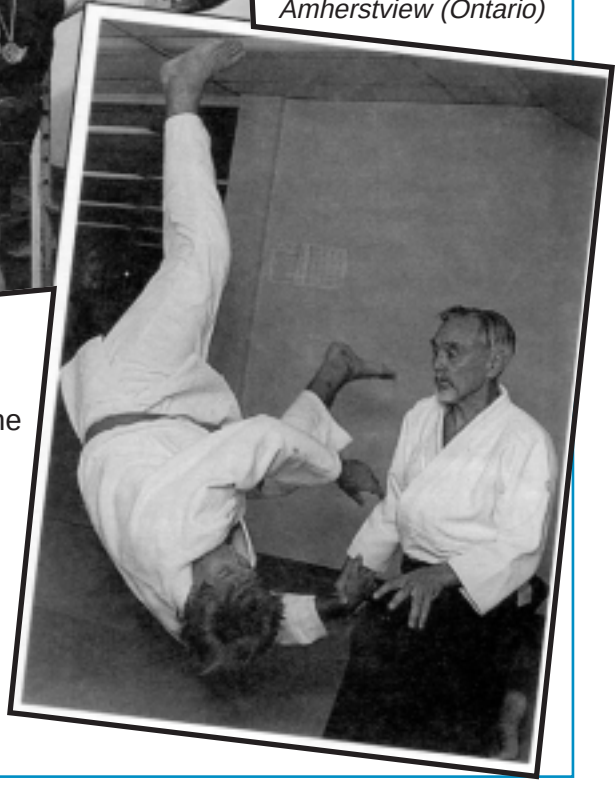
NEWSLETTER OF THE NATIONAL ADVISORY COUNCIL ON AGING

Guest Editorial

Rights and Limits to Risk

Every person is exposed to potential harm simply by living; some people engage in activities - smoking, motorcycling, jaywalking, etc. - that are clearly risky. The extent of risk, of course, depends upon the seriousness of the potential harm and the probability that harm will occur. People generally are free to live 4 at risk', as long as their rights do not infringe upon the rights of others or expose them to harm Nevertheless, as family members, caring friends , service- providers and members of society, we also have a moral obligation to try to protect one another from harm. How can we respect the freedom of the individual to live as he or she chooses, while assuring the best interest of all persons involved?

living at risk when lifting weights or doing judo? Not so, say Sarah Thompson and Bill Bickford, respectively from Belleville and Amherstview (Ontario)



Seniors, particularly older or disabled seniors, may be more exposed to risk of harm than other adults. Losses in physical strength, agility, speed of reaction, vision and hearing may make some seniors more vulnerable to accidents, just in performing the normal activities of daily life. The risk of harm may be compounded by the presence of chronic diseases or by varying mental capacities.
There may be a strong temptation on the part of caregivers and society to override the wishes of vulnerable seniors to protect

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them from possible harm. The dilemma of respecting individual freedom versus protecting a senior from harm is posed in many situations:

• Should seniors continue to live in their own homes if their health or their behaviour exposes them to serious harm?

• Should it be mandatory to report to authorities seniors who are being abused by family or friends and to intervene to protect them?

• Do seniors have the right to refuse treatments that could restore or maintain their I health?

• Should seniors in institutional settings be restrained to prevent injury?

• Should seniors with sensory, perceptual or intellectual impairments be prevented from driving a car?

Making choices about how to live one's life is basic to a person's sense of self-esteem and dignity. However, because their basic security is often an issue, the right of older or disabled seniors to choose to live 'at risk' is sometimes questioned in a way that would never be acceptable in the case of younger adults. The National Advisory Council on Aging (NACA) believes that the rights of seniors to choose to live 'at risk' should be respected as long as the senior is mentally competent and is not likely to harm anyone else.[1]

This principle is simple, but not easy to put in practice. The rights of seniors must be balanced with the legitimate needs and rights of other persons. Evaluating the degree of risk itself is a complex process which must not be done arbitrarily by caregivers. The assessment of mental competency to make decisions is not entirely objective. Finally, respecting seniors' right to make choices that involve risks does not mean withdrawing care and support.

Evan Dickson
NACA Member,
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Freedom and Responsibility

Home Alone

Mrs. X is an 86-year-old widow who has lived alone with the help of home support services for the post ten years. She is on insulin dependent diabetic with a sweet tooth. During the post two years, she has become increasingly short of memory and confused. She often forgets to eat or eats junk food. Efforts to have her live with her only son and daughter in-law several miles away hove foiled. The home core case manager is becoming uncomfortable because, even with the maximum level of home care available, Mrs. X is considered to be at risk. Following a fall, where she fractured her wrist, she was hospitalized. The son, in consultation with home core, decided to institutionalize his mother.

Mrs. X is clearly unhappy in the nursing home, objecting to all aspects of her core and continually asking when she con go home. Nevertheless, the home core agency is reluctant to readmit her into the program because she would require more core than the agency con provide.

Cases like Mrs. X's are not uncommon in home care and create anguish for everyone concerned. A senior's need for home care services may reach the limit that can be provided; yet, the services offered may not be enough to ensure the senior's safety. To ensure protection, the family and formal service-providers may try to override the competent senior's legal and ethical right to self-determination.

Subjective Values and Imprecise Risks

At the heart of the dilemma is a difference in values between the senior and the caregivers. The senior may place a greater value on his or her autonomy and privacy than on personal safety, while the reverse may be true of caregivers. Whose values take precedence? Why should home care's concern for a diabetes-related accident be more important than Mrs. X's desire to eat what she likes? **Dr. Michel Silberfeld**, a Toronto geriatric psychiatrist, challenges the conventional wisdom that leads to conclusions about risk, such as: "People should die in bed and not as a result of an accident."[2]

Assessing risk is itself a risky, imprecise and subjective process. Seldom are there actuarial tables that give the statistical frequency of harm. Usually, a clinical judgment is made in which the health care provider infers, from knowledge of a health condition and its effects, what could happen to a person. However, individual cases often deviate from expectations based on averages. An accident or injury may or may not occur; even if it does, as in Mrs. X's case, what is the likelihood that it will happen again?

Another consideration is the seriousness of the possible harm; sometimes the gravity of the consequences are not clear or can vary in individual cases. To illustrate this, Dr. Silberfeld cites the case of a woman who was theoretically at risk because she neglected taking her medication, but who, in reality, was not in danger because she had never experienced any serious consequences of her disease.[3] Risk assessment is subjective; that is, it is influenced by personal fears or desires. The senior who wants to continue living at home may hope for the best and minimize the risks involved. Caregivers, who fear the worst, can magnify the risk. **Anne Beckingham** and A**ndrea Baumann**, who teach nursing in Hamilton, Ontario, add that major decisions about a senior's care are often made in crisis situations when anxiety over the senior's welfare may prevail over reason in weighing risks and options.[4]

Competency and Risk

The decision that a person is not competent is made in a court of law. The judgment is influenced heavily by an assessment conducted by health professionals. Competency assessments consist of a series of mental tests administered by health professionals to determine if an individual can understand and reason well enough to care for himself or herself. Persons found to be incompetent may lose the right to make decisions for themselves. However, there are several problems in using competency assessments to decide if seniors can exercise the right to live at risk.

First, competency is not all-or-nothing; there are many competencies corresponding to the many tasks one performs everyday - from using electrical appliances to managing one's money. Incompetency in some areas of living does not mean that a person is globally incompetent. Second, the tests used may not accurately gauge the ability to perform many tasks of daily living. **Bill Harvey,** ethicist at the University of Toronto, observes that "There are no universally accepted objective clinical tests of competency for any of the abilities recognized as socially significant in health care or in law."[5] The professional administering the competency test can choose how strict a test to use, depending on the professional's perception of the likelihood that the senior's decisions and actions could harm the senior or others; in other words, in assessing competency, the professional can 'stack the deck' in favour of or against the senior's continued autonomy. Furthermore, if the person fails some aspect of the test, the assessor may arbitrarily infer the consequence of the failure. For example, if a senior is unable to fill in a cheque, the assessor may conclude that the senior is incompetent to manage his or her finances.

Another problem raised by Dr. Silberfeld in competency assessment is that of 'borderline' or of varying competency. A senior who is not mentally competent today may be competent next week and vice versa. Should this person's freedom to make personal decisions be forever decided on the basis of a single assessment?

The criticisms of competency assessment are not made discount its validity entirely but to alert health care professionals, lawyers, caregivers

and seniors that it is subject to bias and that it must be used carefully and the results interpreted with caution. Too much is at stake. **Alan Borovoy**, General Counsel of the Canadian Civil Liberties Association, reflects: "When we are talking about the precious freedom to be left alone, then we should insist that it cannot be lost unless there are the most exacting criteria and the most scrupulous procedures."[6]

Respect and Responsibility'

Steering the right course between respect for individual freedom and concern for the welfare of all may require negotiation and compromise on the part of all concerned. The ethical course may differ case by case and from one time to another.

Vulnerable seniors may have difficulty making their wishes heard and respected by family or caregivers. To assist such persons, the Ontario government has recently passed the Advocacy Act to create a Commission of non-legal advocates who can provide vulnerable persons with information and options they can use as a basis for decision-making and who can ensure that their wishes are taken into account by others. In the new Ontario Substitute Decisions Act, an advocate will also visit persons who are alleged to be incapable of looking after their own personal and financial affairs and for whom guardianship is proposed. The advocate will help these individuals understand the consequences of losing their right to make their own decisions and will provide the opportunity to appeal findings of mental incapacity.

The right of seniors to make choices that involve risk is limited by the effects of their decisions on others. For instance, if there is a significant risk of causing a fire by leaving the stove on in an apartment, the senior's freedom of choice must be balanced with the rights of other residents to a safe environment. Moreover, being part of a family means that one cannot wholly separate one's own interest from the interests of other family members. John Hardwig, a moral philosopher, considers that "To be part of a family is to be morally required to make decisions on the basis of thinking about what is best for all concerned, not simply what is best for yourself."[7] Similarly, insisting on one's right to decide does not entitle one to demand everything one desires. In short, at some point, individual freedom yields to collective rights.

Family and other caregivers are challenged to continue to offer support while stopping short of overriding the senior's decisions and to propose ways of managing risks that respect the senior's values. Respecting a senior's right to choose is not limited to a rule of noninterference; Laurence McCullough and Stephen

Wear, ethics experts, contend that when caregivers defer to the senior's choice, they are, in fact, protecting those values and beliefs that give meaning and purpose to the senior's life and which are so dear that the senior is prepared to make considerable personal sacrifices to uphold them.[8]

The Right to Refuse Treatment

Competent seniors are legally entitled to refuse treatments or other health care interventions. In cases where the senior is terminally ill, it may be easier for health care professionals and family members to accept the decision not to begin a course of treatment that would prolong the senior's suffering. However, when the treatment or intervention could restore the senior's health and functional capacities, it may be tempting to try to disregard the senior's wishes. For instance, how far can caregivers go in trying to make a senior comply with a medication or dietary regimen that would control diabetes? How much can they insist that a senior who has had a stroke undergo physiotherapy or speech therapy to restore functional ability?

When patients refuse potentially life-saving treatments, caregivers may question their mental capacity to consent to treatment. In Ontario, seniors who have refused treatment and who have subsequently been found to be mentally incapable of consenting to treatment are entitled, through the Consent to Treatment Act, to have an advocate inform them of their right to have the incapacity finding reviewed by a Consent and Capacity Review Board.

Responsible caregivers would not simply abandon the competent senior who refused a beneficial treatment. Rather, they would try

to understand why the senior is resisting, to offer appropriate encouragement and incentives and to impress upon the senior the probable consequences of his or her behaviour.
What if a senior chooses to cease a life-sustaining treatment that has already begun? The recent case of Nancy B., a young paralysed Québec woman who asked to be withdrawn from the respirator that kept her alive, provides a precedent in Canadian law. Terri Wilkinson, an Ontario lawyer, interprets the Québec Superior Court decision to mean that "Once treatment begins, it should not be stopped unless the health care provider is convinced that the decision is being made by a mentally competent patient who fully appreciates the risks of non-treatment."[9]

The Recluse

The label of 'recluse' is used to describe socially isolated individuals who exhibit bizarre behaviour and who may resist efforts to reach out to them. **Dr. Barbara Blake** relates the following example:

The neighbours of an elderly woman had seen her eating gross. She had locked herself in her apartment and would not let anyone in. She refused to speak to anyone. She would not accept meals or groceries or money from her neighbours or from the social worker. [10]

It is heart-wrenching for caring people to be unable to provide services to a person in need. However, unless the recluse's actions pose a clear and serious threat of harm to self or to others, service providers cannot legally intervene to impose help in most provinces. The Atlantic provinces have enacted adult protection legislation to allow health or social service agencies to visit a person in apparent self-neglect to offer assistance. An assessment of mental competency may be arranged. If the person is competent and refuses help, services are not imposed involuntarily. In other provinces, the legal mechanism to provide services to a recluse is through guardianship for mentally incompetent persons.

Elder Abuse and Mandatory Reporting

The abuse or mistreatment of seniors has been recognized as yet another manifestation of family violence. Some seniors are subjected to physical or psychological abuse, financial exploitation or neglect of basic needs by trusted persons. A major obstacle to intervention is the reluctance of these seniors to report the abuse. Reasons for under reporting include feelings of shame, isolation from the community, fear of retaliation or abandonment by their families, and fear of being removed from their home.

In the Atlantic provinces, adult protection laws allow for emergency intervention by health and social service providers in cases of abuse. In addition, in Newfoundland and Nova Scotia, reporting of suspected cases to provincial officials is mandatory, while in Prince Edward Island, reporting is voluntary. New Brunswick has no statutory reporting requirement.
Adult protection legislation is challenged by many seniors and professional groups. It is argued that seniors are not children that need to be protected by the State. Defenders of the legislation claim that it is not intended to infantilize seniors, but to offer protection to those who cannot act on their own behalf. Criminologists Robert Gordon and Susan Tomita see other advantages to adult protection laws. They clarify the powers of intervention in cases of abuse and establish a set of procedures for initial and long- term case management. [11] Nevertheless, measures are needed to safeguard individual liberties; these include the right to legal representation, the right of competent persons to refuse assistance and the requirement that any intervention be minimally intrusive and restrictive.

Mandatory reporting is also regarded as a violation of civil rights by some experts. Its usefulness is debated as well, because experience in some jurisdictions (although not all) has shown that voluntary reporting is equally effective in bringing suspected cases of abuse to the attention of service agencies. [12]

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Use of Protective Restraints

In hospitals and long-term care institutions, physical restraints are commonly used to prevent falls, stop wandering or aggressive behaviour and protect medical devices, such as catheters or feeding tubes. Restraints include bedrails, cloth or leather straps and ‘geri-chairs’ (wheelchairs with fixtures to keep the person from rising). Their use is contested on clinical grounds, because they do not appear to decrease injuries from falls or wandering and because restraint may lead to other physical problems, such as muscle deterioration and incontinence. Restraining patients may also violate their moral right to freedom and lead to feelings of humiliation and depression. A 72-year-old man who had been restrained in a hospital said: “I felt like a dog and cried all night. It hurt me to have to be tied up.” [13]

Because restraints are not effective in preventing self-injury, common sense dictates that they not be used for this purpose. If they are proposed and the patient is mentally competent, informed consent must be obtained before they are applied; if the person refuses, restraints are not applied and the person must sign a disclaimer absolving the institution of liability for any resulting injury. Refusing restraint in this instance is the same as refusing treatment. If, however, the person's behaviour could harm others, or if the person is mentally incompetent, the least restrictive measure that assures safety is acceptable, but only for as long as truly necessary.

Alternatives to restraint exist which may be more effective and respectful of the patient's dignity at the same time. **Dr. Roger Roberge** and **René Beauséjour** of La Mauricie Hospital in Shawinigan, Québec, suggest using environmental modifications, such as half-doors, that allow a person freedom of movement in a restricted area. Also suggested are a greater emphasis on occupational and rehabilitation therapies to treat the underlying conditions, as well as enhanced social and emotional support from family, staff and volunteers.[14]

The Freedom to Drive a Car

The ability to drive a car safely may diminish in the presence of physical or mental impairments. Safe driving programs for older adults exist, such as **The Canada Safety Council's** program 'Fifty-five Alive', that teach older drivers strategies to compensate for decreased abilities and discuss when seniors should quit driving voluntarily.

Because of the danger to others posed by unsafe driving, there are legal qualifications to the right to drive in every province based on age or on health status. The laws, however, vary widely. For example, in Ontario, drivers aged 80+ must take a written and practical driving test as well as a vision test each year to have their licence renewed. In Alberta, drivers aged 75 are required to submit a medical report attesting that they are capable of driving; this medical clearance must be renewed again at 80 and every two years afterwards. Several other provinces, including New Brunswick, Nova Scotia, Prince Edward Island and Manitoba, impose no age criterion for licensing drivers. Nevertheless, in most provinces, a physician who discovers that a person has impairments that can affect driving safety is legally obliged to report the disability to the provincial licensing authorities, who may revoke the driver's licence.

The presence of disabilities that impede driving is not always obvious, either to the person or to the doctor. If family and friends notice that driving is impaired, they may have the moral responsibility to persuade the senior to stop driving, to prevent him or her from using a car or, depending on the province, they may be required by law to report the senior's impediments to licensing authorities.

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Dignity of the Person

The freedom to make choices in life is a primary source of personal dignity and is a cornerstone of a democratic society. To uphold the right of competent persons to live at risk is to reaffirm this value. Yet the principle of dignity of the person also applies to those who can no longer make personal choices. An ethical course is to restrict individual freedom only if necessary and only as much as necessary.

Fact File

• 1.7% of Manitoba seniors were hospitalized in 1984 as a result of an injury.
• 66.3% of all hospitalizations of seniors resulting from injury were for accidental falls; nursing home residents were more like be hospitalized after a fall than community dwellers.
Shapiro, E. Hospital use by elderly Manitobans resulting from an injury. *Canadian Journal on Aging,* 7, 2, (1988): 125- 133.

• A survey of almost 3,000 patients in Québec long-term care institutions revealed that 47% were being restrained, mostly with physical restraints.
Roberge, R. and R. Beauséjour. Use of restraints in chronic care hospitals and nursing homes. *Canadian Journal on Aging*, 7, 4, (1988): 377-38 1.

• The probability of restraint use increases with the age of the person/patient and the severity of cognitive impairments.
Evans, L.K. and N.E. Strumpf. Tying down the elderly: A review of the literature on physical restraints. *Journal of the American Geriatrics Society*, 39, (1989): 792-798.

• In institutions where the use of restraints has been discontinued or severely curtailed, there has been no increase in serious injury.
Evans, L.K. and N.E. Strumpf. Myths about elder restraint. *Image: Journal of Nursing Scholarship*, 22, 2, (1990): 124128.

• At least 4% of community dwelling seniors in Canada are victims of abuse by trusted persons.
Podnieks, E. et al. *National survey on abuse of the elderly in Canada: The Ryerson Study*. Toronto: Ryerson Polytechnical Institute, 1990.

• Over 30% of persons with by Alzheimer's disease (AD) still drive.
• In study of drivers with AD, 47% were involved in a collision over a five-year period.
• 76% of drivers with AD believed there was no problem with their driving, whereas only 26% of the caregivers of these persons thought there were no problem.
Alzheimer Society of Canada. *AlzheimerRapport*, 12, 6, (Winter 1990): 1-2.

Tips List

For seniors

• Insist in being fully informed about options before consenting to treatment or services.
• Insist in participating fully in I decisions about your life, even if you depend on others to do things you can no longer do for yourself.
• Consider the consequences of your wishes and preferences on people you care about when making decisions about how you want to live.
• Consider the longer-term effects of decisions you make today; complying with the directions or advice of others now may help enhance or maintain your autonomy in the I future.
• Be open to information and advice from family and service-providers and to the possibility that you could be happy living in another place or in another way; adaptability is as important for your well-being as determination.

For family members and caregivers

• Provide clear and full information to seniors about services or treatments to ensure their informed consent.
• Through discussion, explore ways of helping seniors manage risks before considering coercive measures.
• Inform seniors living at risk of the limits of the care and support you can provide, based on your rights as an individual and your responsibilities to other family members or to other clients.
• Avoid a laissez-faire approach to seniors who insist on living at

risk; you remain morally or professionally committed to ensuring their well-being, to the limit of their choices and your own resources.
• If a senior's decision or behaviour appears irrational to you, try to understand the perspective of the person and what matters to him or her before questioning the senior's mental competence.
• Recognize that competency is multi-faceted and specific to particular situations, instead of concluding on the basis of an assessment that a person is globally incompetent; in borderline cases, consider repeating the assessment at a later date.
• Respect the freedom of the senior to make choices in areas where he or she remains competent.
• In areas where a senior has been found to be incompetent, restrict the person's freedom as little as possible.
• Use occupational or rehabilitation therapy in combination with personal supervision rather than restraints to control potentially harmful behaviour in institutions.
• Gently but firmly prevent a person whose mental or physical impairments cause driving problems from having access to a car, and report the impairment to the person's doctor or to licensing authorities.

For Further Reading...

Please refer to your library for a copy of these publications.

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Notes

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2 Silberfeld, M. The use of 'risk' in decision-making. *Canadian Journal on Aging,* 1 1, 2, (1992): 124-136.

3 Ibid.

4 Beckingham, A. and A. Baumann. The ageing family in crisis: Assessment and decision-making models . *Journal of Advanced Nursing,* 15, (1990): 782-787.

5 Harvey, W., Ethics in the health care of the elderly person. In National Advisory Council on Aging (ed.). *Ethics and aging.* Ottawa: the Council, (1993): 57.

6 Borovoy, A. Guardianship and civil liberties. *Health Law in Canada*, 3, (1982): 57.

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A MESSAGE FROM

NACA'S NEW CHAIRPERSON

It is a privilege to chair theNational Advisory Council on Aging.

The 1980 mandate of this Council was "to assist and advise... on all matters related to the quality of life of the aged," whether referred by government or ' considered appropriate' by Council.

The Council, under four distinguished chairpersons and with a dedicated and skilled secretariat, has been faithful to this mandate. During the past 13 years, NACA has become a respected adviser to government. It has developed a national, and even international, reputation for the quality of its publications. It is a resource centre for seniors' organizations. Formal 'Position Papers' have reflected Council's opinions on major topics, while the 'Writings in Gerontology' have promoted discussion on new, and often controversial, themes.

It has been my good fortune to have served on the Council for the past three years, during Dr. Blossom Wigdor's term as chairperson. I hope I can bring, to our deliberations, some measure of her experience and wisdom.

NACA has not become a 'lobby for seniors,' nor does it represent a 'Special interest group'. The large and growing population of older Canadians is too diverse for that.

The role of the Council will be to continue to reflect, to government and to the country, those matters which pertain to the quality of life of seniors as inseparable from the quality of life of all Canadians. Childhood, adulthood and elderhood are a continuum. Daunting problems will come before Council in the next few years. As a nation, we must reconcile access to appropriate health care for the elderly with protection from inappropriate technology. We must find, in a world of 'mandatory retirement,' a place for those who can and should continue to make their skills available to the common wealth; yet, also support a decent quality of life for those who can no longer work. There will be other questions to be answered, some not yet imagined.

NACA will continue to serve this nation and this government with thorough research, timely publications, careful deliberations and honest advice.