THE CHARLOTTETOWN DECLARATION ON THE RIGHT TO CARE[1]

The Right to Care

Canadian society has a collective responsibility to ensure universal entitlement to public care throughout life without discrimination as to gender, ability, age, physical location, sexual orientation, socioeconomic and family status or ethno-cultural origin. The right to care is a fundamental human right.

The Right to Care requires:

- **Access to a continuum of appropriate, culturally sensitive services and supports**
- **Appropriate conditions**
- **The choice to receive or not receive or to provide or not provide unpaid care**
- **That there is no assumption of unpaid care**
- **Access to reasonable alternatives and sufficient information**

Care is:

- **Essential**
- **An interdependent relationship**
- **Skilled work**
- **Multidimensional**
- **Diverse**

Care should be:

- **Equitable**
- **Available**
- **Accessible**
- **Continuous**
- **Responsive and transparent**
- **Incorporating an awareness of diversity**
- **Participatory**
- **Enforceable**
- **Standards-based**
- **Publicly administered**
- **Respectful**

Charlottetown Declaration on the Right to Care

These rights to care must be viewed through a lens that recognizes the importance of gender analysis, diversity, interdependence between paid and unpaid care, and linkages among social, medical and economic programs.

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[1] This document is based on a "National Think Tank on Gender and Unpaid Caregiving" organized by the National Coordinating Group on Health Care Reform and Women and the Maritime (now Atlantic) Centre for Excellence in Women's Health, November 8 - 10, 2001 in Charlottetown, PEI. Forty-six of the fifty-five participants signed the Declaration. Some were not in the position to commit their organization or government department. For more information see www.cewh-cesf.ca/healthreform

The Origin of the Charlottetown Declaration on the Right to Care

In Charlottetown in November 2001, 55 experts from the academic, policy and caregiver communities gathered to discuss research and policy on women and home care. Based on their experiences and the existing research literature on gender in relation to home and community care, these experts concluded that women's experiences and needs are often different from those of men.

- Women are the majority of those who receive care
- Women are the majority of those who give care
- Women are more often expected to provide care
- Women have fewer financial resources to provide care
- Women provide more demanding care, work longer hours, and have more responsibility
- Women's lives and plans are more disrupted by caregiving
- Women have more extensive and supportive networks, however these networks may also be a source of conflict
- Women with care needs receive fewer hours of paid care

Existing conditions for caregiving mean that:
- Women providing care often end up in poor health
- Women are rewarded by caregiving, although inadequate resources limit rewards and make it harder to care
- First Nations, Inuit and Métis women face persistent and pervasive obstacles in giving and receiving care
- Women from immigrant, refugee, and visible minority communities may face racism in giving and receiving care as well as language and cultural barriers
- Women receiving and giving care are often subject to violence and other physical risks
- Women are facing deteriorating working conditions, low wages and lack of security in providing care

The workshops and plenary discussions led to a consensus on the fundamental principles for a national home care strategy that ensures equity for both women and men. These were codified into the Charlottetown Declaration on the Right to Care, which recognizes that home care needs to be an integral part of a publicly administered health care system.

Understanding the Declaration

The right to care is a fundamental human right.[2] This means that Canadian society has a collective responsibility to ensure universal entitlement to public care throughout life. Such care must be provided without discrimination as to gender, ability, age, physical location, sexual orientation, socio-economic and family status or ethno-cultural origin. Care is thus understood as a public good rather than as a private one to be bought individually for a price. Care is not like a car or other consumer goods. Furthermore, access to care should not depend on a person's ability to pay.

The right to care requires access to a continuum of services and supports. Our public health care system began initially by financing hospitals and then moved on to pay for physicians. But the Hall Royal Commission that led to medicare clearly understood an effective and efficient public system had to provide a full range of co-ordinated services and supports, including public home care. Indeed, the Commission saw the financing of hospitals and doctors as merely the first step, because only with a continuum of services would people receive care at the most appropriate level, move easily from one service to another and avoid costly duplication. Such a continuum in public care does not currently exist. In addition to services, care givers and those receiving care need supports such as training, paid leave to provide care, job security and income programs. The particular preferences of those giving and receiving care must be taken into account – such services and supports must be culturally sensitive**.**

The right to care requires appropriate conditions. Whether care is provided at home or in a facility, it is necessary to provide conditions that meet the needs of care recipients and care providers. We know that health is determined by culture, physical and social environments, social support, security, gender, economic and educational resources, and coping skills, as well as by biology, genetic makeup and health services. These all count in the provision of care, and some are even more important, given the fragility of people who are ill or have a disability. Homes are not necessarily havens and hospitals can be dangerous to the health of patients and providers if conditions do not meet their particular needs or ignore the determinants of health.

The right to care requires the choice to receive or not receive, or to provide or not provide unpaid

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[2] Statements in bold are direct excerpts from the Charlottetown Declaration.

care. Care involves both the person who gives care and the person who receives care. Both need choices about who provides care and about what care is provided. As the Prime Minister's National Forum on Health was told, women "conscripted" into care end up in poor health and may be unable to provide adequate care. Women who need care may not want to receive such care from relatives conscripted into service. At the same time, many want to provide care or to receive assistance from relatives but need help to do so. Public care should provide alternatives in ways that offer a genuine choice for those involved in the care relationship.

The right to care requires that there is no assumption of unpaid care. Care is not a choice if it is assumed families in general, and women in particular, are willing and able to provide care. Many lack the skills, other resources or desire to give or receive unpaid care. The majority of women are in the paid labour force and rely on that income to live; this may leave them with little time, energy or desire to take on unpaid caregiving. Moreover, care work at home increasingly requires complex treatment (e.g. managing respirators, tracheotomy tubes, or dialysis equipment, etc.) which not all are able to undertake. At the same time, unpaid care may not be possible without other necessary supports.

The right to care requires access to reasonable alternatives and sufficient information. The right to care requires not only a choice about providing or receiving care but also a choice about how and where care is provided.

For many, but not all, the home may be the best place for care. For some, but not many, facilities may best serve their needs. Such alternatives must be available to ensure appropriate and culturally sensitive care. Moreover, reliable, accessible information on the benefits of and problems with alternatives and on how to access them, as well as on how to give and receive care, is a necessary component of a public care system.

To ensure the right to care, **care must be understood as essential**, something we must provide as a country. While we have choices about how, when and where to provide care, we do not have a choice about whether to provide care to those who need it. We cannot leave people without necessary care. Care must also be understood as **an interdependent relationship**. It is not simply about what one person does to or for another but also involves reciprocity. It frequently involves paid and unpaid care providers, extended family and friends, as well as the person receiving care.

Care is **skilled work**, requiring education, training and experience. It is not something women do naturally by virtue of being women. Care is at the same time **multidimensional**, involving all aspects of those involved in the relationship. It includes everything from feeding, injecting and hugging to bandaging, chatting and intubating. And finally, care is by definition **diverse**. People are different. Their cultures and experiences shape their needs and how those needs ought to be addressed.

Care should be:

Equitable. Equitable care does not mean the same care for everyone. Rather, it means a fair distribution of care based on appropriately assessed needs, and a fair distribution of care work. The *Canada Health Act* defines equitable as care provided under "uniform terms and conditions," and this principle should apply to homecare.

Available. Available care means public services provided within a reasonable distance without unreasonable delays. The *Canada Health Act* recognizes that care must be there to be accessible, and this principle should also apply to homecare.

Accessible. The *Canada Health Act* says that necessary services must be provided in a manner that "does not impede or preclude either directly or indirectly" access to care. This includes user fees or other charges that can undermine the right to care. The accessibility principle from the *Canada Health Act* should apply to homecare.

Continuous. Care does not only require that there be a smooth transition among services and a range of services to provide appropriate care. It also requires continuity in care providers and services.

Responsive and transparent. Care should respond to the particular needs of those giving and receiving care. People need to know how to access services that respond to their needs and how decisions about services are made. This includes decisions about what care is publicly provided and what is not.

Incorporate diversity. Responsive care recognizes cultural, regional, age and gender diversity, as well as differences related to sexual orientation, and socio-economic and family status. Particular attention must be paid to traditional practices and activities of First Nations, Inuit and Métis peoples.

Participatory. Both those providing and those receiving care should be involved in decisions about how, when, where and by whom care is provided. And, the public should be part of the process in determining how the system is organized and how care is delivered.

Enforceable. It is not enough to set out the principles for the right to care. It is also necessary to put mechanisms in place to ensure that these rights are protected through the provision of services and supports that protect this right.

Standards-based. It is important to respond to individual needs and to allow individuals to participate in decisions about care. However, it is also necessary to have standards for care based on evidence about the effectiveness and the appropriateness of care. Evidence should provide guidelines for providers and standards against which care can be compared.

Publicly administered. There are clear benefits to a publicly administered health care system in terms of cost savings and co-ordination. It is also easier to hold a publicly administered system accountable to citizens.

Respectful. Those providing both paid and unpaid care, as well as those receiving care, must be treated with respect. Respectful care recognizes that individuals have preferences, abilities, feelings, knowledge, and histories.

The Right to Care must recognize the importance of gender analysis, diversity, interdependence between paid and unpaid care, and linkages among social, medical and economic programmes.

A Call to Action:

The Charlottetown Declaration was a product of deliberations on existing research, practice and experience. It provides the principles for further action on developing a comprehensive public system that includes home care and works for both women and men.

Further Information:

Marika Morris, *Gender-sensitive Home and Community Care and Caregiving Research: A Synthesis Paper*. 2002.

National Coordinating Group on Health Care Reform and Women. *Proceedings of the National Think Tank on Gender and Unpaid Caregiving*. 2002.

National Coordinating Group on Health Care Reform and Women. *Women and Health Care Reform*. Revised ed. 2002.

National Coordinating Group on Health Care Reform and Women. *Women and Home Care*. 2002.

To order the above publications see:
www.cewh-cesf.ca/healthreform

National Coordinating Group on Health Care Reform and Women: Who we are

We came together in 1998 as a collaborative group of the Centres of Excellence for Women's Health (CEWH), the Canadian Women's Health Network and Health Canada's Women's Health Bureau. Our mandate is to coordinate research on health care reform and to translate this research into policies and practices. More information about our work is available from our web pages at www.cewh-cesf.ca/healthreform.

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