

women *and Home Care*

Why does Home Care Matter to Women?

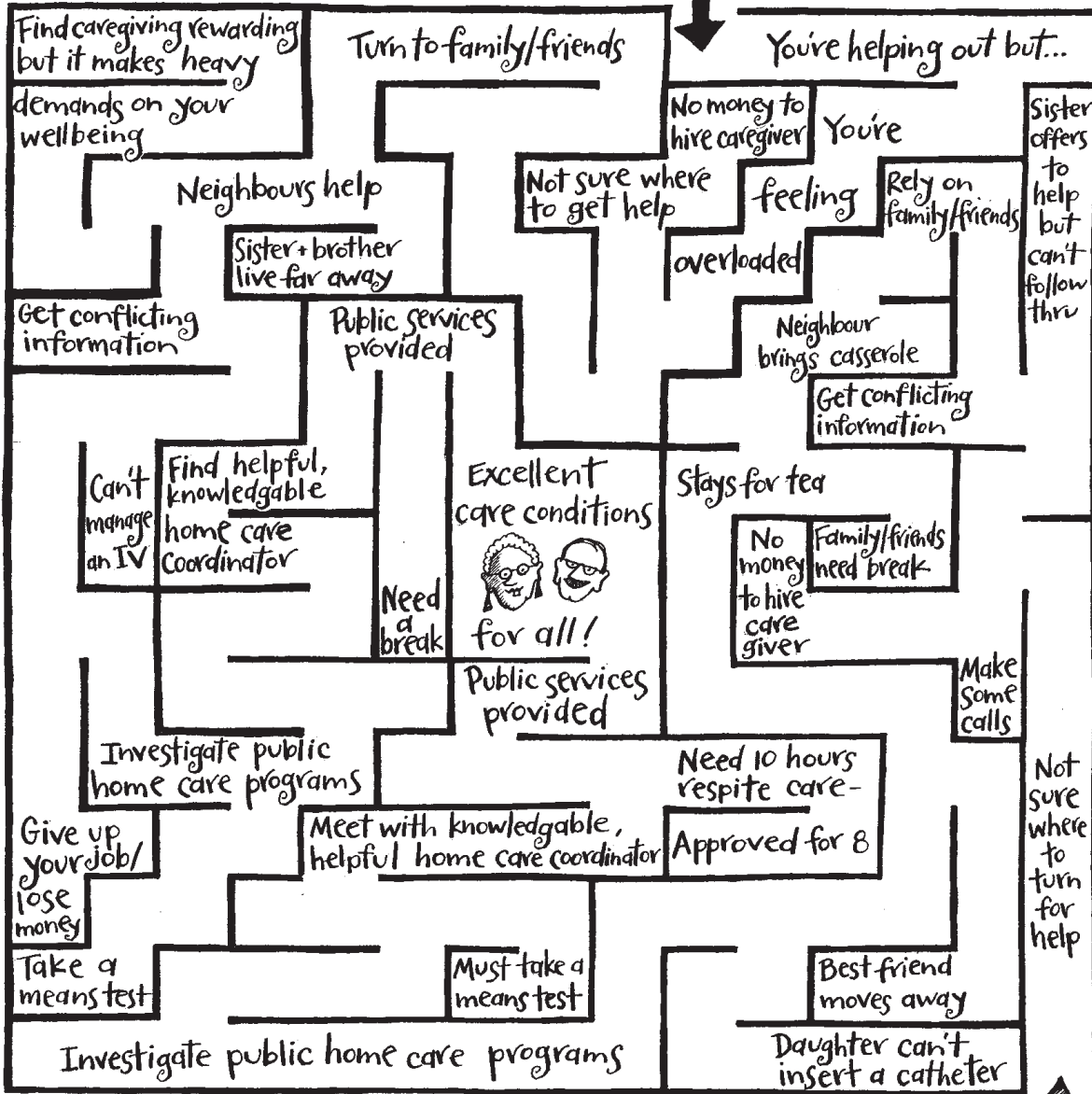
Care in the home is women's work. Women provide more than 80% of paid home care. Women also provide a similar proportion of the unpaid personal care for the elderly and for those of all ages with long-term disability or short-term illness. Moreover, women are a majority of the volunteers in the community who do personal care work.

There is nothing new about women doing the bulk of the paid and unpaid caregiving. What is new is the kind of care that is provided at home, the number of people who are cared for at home, the small number of people in households available to give care, and the participation of most women in the paid labour force. Health care reforms mean more and different work at home for women. Although caregiving is often rewarding, it can also have long-term consequences for women's health, their other work and their financial well-being. And poor conditions for care can mean that those who receive care—most of whom are also women—get poor care.

Key Questions about Home Care:

- What is home care?
- Who provides what kind of care?
- Why is home care an issue?
- What are the costs of home care?
- What are the conditions of home care?
- What can be done about home care?

Someone you know needs care!



You need care!

What is Home Care?

It may seem obvious that home care is about care provided in the home, care given where people live. Indeed, this is how the term is used here. However, home care means different things to different people. It is therefore important to be clear about what is being discussed when the term “home care” is used.

Home care has such different meanings in part because there is so much variation among households as well as in individual care needs, and in part because even in the same household, home care may not mean the same thing for each of the people living there.

Home care also has different meanings because care involves a wide variety of both simple and complex activities. It often takes different forms—forms related to the culture, gender, economic status and geographical location of the people involved. It is possible, however, to identify kinds of activities involved in home care.

First, home care includes both paid and unpaid care. In paid work, the boundaries are usually relatively clear. Policies and contracts set out what care is provided for how long by which people. (Still, in some situations the entitlements are not clear, and the expectations placed on paid care providers by clients and family members may not match the tasks set by the home care agency.) In unpaid care, the boundaries are more difficult to establish and so are limits on how much time is devoted to care.

Hidden in the household and done mainly by women who do a range of other domestic work, care work is often invisible. Yet this invisible work accounts for the overwhelming majority of care provided today. More care is paid for now by public health care plans, by insurance companies and by individuals compared to a decade ago. However, such care is understood as a *supplement to*—rather than a *substitution for*—care by family, friends and volunteers, as a way to fill in the gaps in unpaid care. Research indicates that between 85% and 90% of all care is unpaid, even when hospital and other institutional care is included in the calculations.

Second, both paid and unpaid providers are involved in coordinating and managing care. They assess what care is required and figure out how, when and where to get it. They negotiate for care, mediating between paid and unpaid providers and between providers and those who receive care. They handle money and accounts, keep records of care and medical test results. They often juggle conflicting needs of those who provide and those who receive care, as well as a host of complicated appointments and expenditures.

Third, home care frequently means medical and nursing care. In addition, a significant amount of home care involves personal care—what in the language of the health care system are called ‘Activities of Daily Living’ (ADL). These activities can range from bathing, feeding, walking and dressing to inserting tubes, giving needles and attaching oxygen masks.

Fourth, home care often involves assistance with regular household tasks, or ‘Instrumental Activities of Daily Living’ (IADL). When people become ill, are released early from hospital, have more long-term disabilities or simply become more frail as they age, they require help with cooking, shopping, cleaning,

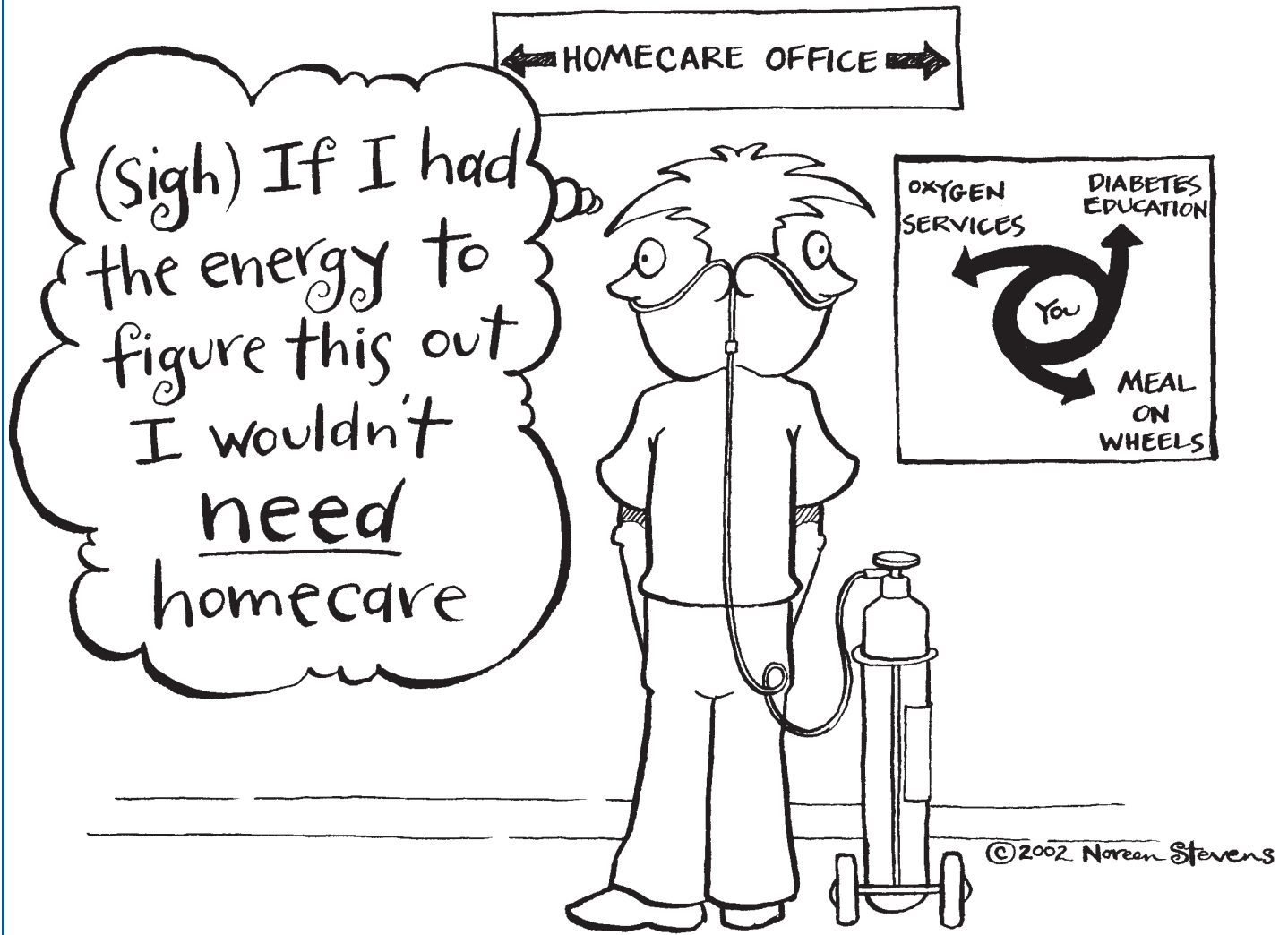
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What is Home Care? cont'd

laundry and home maintenance. Although most of this work is done without pay, many people do not have anyone available or able to take on this unpaid work. Research carried out in British Columbia shows that paid assistance in these areas can mean the difference not only between staying at home and entering a facility but also between life and death.

Fifth, home care involves social and emotional support. Such activities are the most invisible, but they are nonetheless critical to care and individuals' well-being. Everyone needs support. However, those who have undergone surgery, suffer from terminal illnesses, experience long-term disabilities or live into frail old age have particular needs for companionship, comfort, conversation and attention. Indeed, such support (or the lack of it) can have a profound impact on health. Too often, those needing care are isolated in individual households. Or they are isolated from those who live with them and from those who provide paid care but who have no time to do anything but quick tasks.





One, some or all of these home care activities may be provided, and they may be provided by one person or by many people at the same time or a different times, in the same place or in different places. There is also an incredible range in the complexity of the care provided, depending on the age and health problems of the care recipient, and the capacities of the care providers.

While homes are often pictured as warm comforting and supportive places for care, especially compared to institutions, this is not necessarily the case. Homes may not be the most appropriate place for a variety of reasons. For example, relationships in the home may be characterized by conflict or violence. Members of households may not have the skills or capacity to provide the kinds of care required. Households may be overcrowded or simply physically constructed in ways that make it difficult to care. And homes may be located too far from critical services. Home care is not an alternative for the growing number of people who do not have homes at all.

Who Provides Care and What Kind of Care Can/Do They Provide?

The clear answer to the “Who provides?” question is **women**. As mothers, daughters, partners, friends, volunteers and as employees or self-employed professionals, women provide the overwhelming majority of care in the home.

As unpaid caregivers, women are much more likely than men to provide personal care and offer emotional support. Men’s contribution is more likely to be concentrated in care management, household maintenance, shopping and transportation. In other words, women are more likely to provide the care that is daily and inflexible while men provide care that can be more easily planned and organized around paid work. And men are more likely than women to get paid help when they provide care, based on the twin assumptions that men must do their paid jobs and that men lack the skills necessary for the work. Yet women provide, and are expected to provide, unpaid care even when they have jobs in the labour market and even when they do not have the skills required to provide the complicated care work now done at home.

Although women are much more likely than men to be “conscripted” into unpaid care, there are differences among women in terms of what care they provide and the choices they have about providing care. Income, education and geographical location matter at least as much as cultural traditions in terms of the kinds and amounts of care women provide. The poorer a woman is, the fewer choices she has. The more rural her location, the more hours of care she provides. Caregivers in many immigrant and visible minority communities often face racism, language and cultural barriers in their search for support. Aboriginal women are frequently disadvantaged and poorly served. Lesbian and gay caregivers also experience discrimination in their efforts to provide care. And mothers of children with disabilities account for 96% of the primary caregiving in their households, clearly indicating that care work is not equally distributed nor do care providers face equal conditions for care.

Women are also paid to provide a range of services in the home. Nurses and therapists, homemakers and care aides are most likely to be women. Many are immigrants. It is not uncommon for these women to have obtained medical or nursing education in their countries of origin, education that is not recognized in Canada. Hundreds of foreign-trained nurses have been recruited into Canada on temporary work permits through the government’s “Live-in Caregiver Program”. Supposedly recruited as domestic workers, they in fact provide very low cost 24-hour nursing care. They bring an impressive range of skills to their job but their skills are not acknowledged in their job title or their pay.

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Why is Home Care an Issue?



There are a number of reasons why home care has become an increasingly critical issue.

First, health care reforms are sending more care, and more complex care, home. Patient stays in hospitals are shorter, there is more day surgery and more services are provided on an out-patient basis. Psychiatric and chronic care hospitals have been closed, and the total number of beds in all Canadian hospitals significantly reduced.

Cost cutting strategies, combined with new developments in medical techniques, mean people are sent home quicker and sicker or not sent into institutions at all. It is now possible to give at home oxygen and intravenous injections, as well as a host of other treatments once provided only in a hospital. And it is cheaper for the public system, at least in the short term, to have care provided at home. It is cheaper because when people are sent home for care, both the care work and care costs are shifted away from the public system. Drugs and treatments otherwise covered in institutions become mainly private costs in the home.

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Why is Home Care an Issue? cont'd

Second, changing ideas about health care also play a role in these developments. Increasingly, institutions are seen as inappropriate or even unsafe places to be, while homes are simply assumed to be both appropriate and safe. Care is increasingly defined as a private rather than a public responsibility, even though the evidence clearly shows that public care is cheaper, more accessible, and at least as effective as care based on individual payment or delivery.

More care work and care costs sent home necessarily means greater inequality among those who give and receive care, because those with money are better able to pay for care. Home care is not covered by the *Canada Health Act* principles that require universal access. Thus in some provinces, means tests, user fees and eligibility requirements have been introduced that also contribute to inequality. What this means is that some people are denied access to needed care simply because they do not meet the eligibility requirements, or are unable to pay the required user fees.

Third, more people have chronic diseases, including people living with HIV/AIDS. People with severe disabilities are living longer. Most of them live at home, and many need considerable care. A higher proportion of the population is elderly. Women form the majority of the elderly as well as a significant proportion of younger people with health problems. They are more likely than their male counterparts to have their care needs unmet.

It cannot be assumed, however, that the “aging” of the Canadian population will translate into skyrocketing health care costs or increasing dependency on home care. Many of those entering old age are in far better health than their parents and grandparents were and thus may well live without extensive care needs. Aging is not necessarily a process that results in increasing reliance on health care services, and there are significant variations among the elderly in terms of needs. Some of the high costs have been created by the way we treat the elderly. Such costs can best be addressed by assessing the appropriateness of elder care. Other costs can be reduced by providing supports such as housing.

Fourth, there are fewer people in the home to provide care and even fewer who have the skills required to provide the kind of care being sent home. Birth rates have declined, and even though children remain dependent on their parents much longer than in the past, most live away from the family home once they reach adulthood. Although rising housing costs and policies such as immigration rules that require families to support dependents are contributing to a small growth in families sharing households, most homes house no more than three or four people and many have only one occupant. Most women are now doing paid work, and taking employment for the same reasons men do. Only a minority have the possibility of staying home full-time.

Consequently, just as more care is sent home, there are fewer people to provide care. It is important to note, however, that this is not care being sent *back* home. The kinds of complicated care now provided at home were never provided there in the past, so households in general, and women in particular, are facing new care demands.

Conditions for Home Care

Home may provide supportive environments for giving and receiving care, a place where people can be surrounded by their familiar things and retain some control over their lives. Much depends, however, on the nature of their health care needs, on the nature of their households and on the nature of supports available.

For paid providers, working in a home can mean they have some independence and variety in their work. But it can also mean isolation, working without the kind of equipment or support that makes work safe, continually facing unfamiliar conditions that make care difficult to provide and the risk of violence or other abuse. Health and safety standards are more difficult to establish or apply. In addition, working in a home means dealing with the often conflicting demands of family and friends. Those who provide care in the home are usually paid less than their counterparts who work in hospitals or long-term care facilities.

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Conditions for Home Care cont'd

They are less likely to be protected by a union, or to have benefit packages. Few have formal training. Many work on a casual basis and have to travel long distances among homes without being paid during that time. The increasing emphasis on cost cutting means they have less time for each visit and less control over their work.

Unpaid providers often gain considerable satisfaction from providing care at home, but they face many of the same adverse conditions as paid providers. They have the additional stress of juggling other household demands and, frequently, of providing intimate care for a family member. Even fewer of them have training for the job, and care demands may create conflicts with both paid providers and other unpaid ones. Perhaps most importantly, unpaid caregivers may have no control over when, for how long, and whether they provide care because there is no or little public support available.

Those receiving care may experience a loss of control if supports are denied, or if the care provided fails to reflect their culture and individual needs. Both paid and unpaid providers may invade their privacy, and hospital equipment squeezed into their home may not only make it unfamiliar but also dangerous. The danger may be increased by the difficulty in maintaining a clean environment, getting access to appropriate food, problems with the disposal of medical waste, and isolation. Moreover, cost cutting strategies may mean those needing care seldom have the same caregiver over time and instead face a changing parade of individuals, each of whom is a stranger with somewhat different ways of providing care, often for very intimate tasks.

When we talk about the conditions of care, it is hard to ignore the fact that more and more, the system seems to be asking, “how little care can we get away with?” rather than “how well are the services matched to assessed needs of clients?” or “how do deteriorating conditions of care affect providers?” Clearly, more attention needs to be focussed on ensuring good quality home care that does not result in further stresses on paid and unpaid care providers, and on those who receive home care.

It is hard to ignore the fact that more and more, the system seems to be asking, “how little care can we get away with?” rather than “how well are the services matched to assessed needs of clients?” or “how do deteriorating conditions of care affect providers?”

What are the Costs of Home Care?

The focus in health care reforms has been on financial costs. It is assumed that home care reduces public costs, primarily because much of the care cost and care work is shifted to the individuals and households, and because providers paid from the public purse for home caregiving are paid less than those working in facilities. Surprisingly little research has been done to test this assumption, especially research that looks at long-term private and public costs.

Research has, however, been done that shows the costs are especially high for women if we consider not only financial but also health costs. For women, unpaid caregiving can mean career interruption, time lost from work, income decline and a shift to part-time work or even job loss. These costs are felt far into the future in terms of low or no pensions, and a loss of social contacts and satisfaction from paid work. But many of the costs are more difficult to see or measure.

The physical demands of care, especially combined with little training or supports and time-pressures, can lead to exhaustion and frequent injury, as well as headaches, chronic diseases and a greater vulnerability to illness. Conflicts often arise with paid caregivers, and among the unpaid ones, frequently disrupting support networks. Women unpaid caregivers report feeling guilt—guilt about being healthy, about not

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My sister in the city has three doctors, a chiroprapist, a physiotherapist, a home care worker and meals on wheels. Out here, all I've got is a can opener and a box of band-aids



What are the Costs of Home Care? cont'd

understanding the illness, about not making the right choice for those receiving care, and about feeling trapped. The guilt is compounded by their role as confidante and decision-maker, and by cultural and other pressures assuming women who care about someone must also care for them. They suffer from depression and stress. The pressures are particularly acute for those unable to afford private support services or get public ones because of eligibility rules or their geographical location.

Those receiving care face obvious and less obvious costs as well. Drugs and equipment provided in facilities are seldom paid for by public home care services. Renovations are often required, as well as special supplies. Public home care services, and eligibility criteria, vary considerably from jurisdiction to jurisdiction, but most charge some fees for at least some of the services they provide. Recipients too frequently feel guilt both about using the public system and about depending on the daughters, mothers and spouses, or less frequently, sons and friends. Moreover, care by untrained providers or restricted hours of paid services may mean they receive less than adequate care. The consequence can be a deterioration in health that leads to a long-term care facility, and thus greater public costs.

Caregiving and receiving also has benefits and rewards. But these rewards and benefits are hard to realize in the absence of support, relief and choice about giving or receiving care.

What can be Done About Home Care?

Health care reforms are creating a hidden health care system, one that has high costs for the women who give and receive care and offers them little choice about giving or receiving care. The combination of sending people home for care and the absence of an adequate public home care program not only reinforces notions about care work being women's work but also conscripts women into unpaid care and limits their possibilities for paid work. If women went on strike and stopped providing care at home, home care would collapse, and the health care system would be overwhelmed.

The National Forum on Health, a group of experts appointed by the Prime Minister in the mid 1990s to examine the future of health care, recommended a national public home care program. A home care conference following their report strongly supported this recommendation, as did a think tank held in November 2001 that focussed on gender and unpaid care. The think tank brought together home care researchers, policy analysts and care providers. The 2002 report of the Royal Commission on the Future of Health Care in Canada (Romanow Commission) recommended that a "national platform for home care services" be enshrined in an expanded Canada Health Act and that certain aspects of a national home care program be implemented immediately. There is clearly a consensus that a public program would be more efficient, effective, accessible and equitable than a piece-meal mix of private and public systems. And it is necessary if women are to be healthy.

Such a national home care program must be based on the recognition that home care is a women's issue, must value care work and make care work a choice for women as well as for men. To ensure appropriate care, it must be part of an integrated system that also allows the option of care in a facility that offers appropriate services and that provides the conditions for continuous care by a stable workforce. To ensure that women who choose to can provide care, it must be accompanied by supports such as respite care and access to 24-hour services. To ensure that women are not punished for staying home to give care, it must be combined with employment supports such as family leave and pension provisions, changes in tax laws and income maintenance programmes. For those who are paid to provide care, it must ensure decent working conditions such as adequate pay and appropriate training. Only then will women have the right to care.

The 2002 report of the Royal Commission on the Future of Health Care in Canada (Romanow Commission) recommended that a "national platform for home care services" be enshrined in an expanded Canada Health Act and that certain aspects of a national home care program be implemented immediately.

Where to Find More Information on Home Care

Publications: Centres of Excellence for Women's Health (CEWH):

- "Who Cares: The Costs and Benefits of Caregiving," CEWH *Research Bulletin*, Vol. 3, No.1, Spring 2002. Available at www.cewh-cesf.ca/bulletin/index.html or from the Canadian Women's Health Network (CWHN).
- "It's time to act on home care" and "National home care program a woman's issue" in *CWHN Network*, Vol.5, No.2/3, Spring/Summer 2002. Available at www.cwhn.ca/network-reseau/5-3/5-3pg1.html or from CWHN.
- The Objective is Care: Proceedings of the National Think Tank on Gender and Unpaid Caregiving, November 8 – 10, 2001, Charlottetown, PEI. Available at www.cewh-cesf.ca/healthreform/default.html
- Charlottetown Declaration on the Right to Care, CEWH, 2001. Available at www.cewh-cesf.ca/healthreform/default.html or from CWHN.
- Marika Morris, Gender-sensitive Home and Community Care and Caregiving Research: A Synthesis Paper, CEWH, 2001. Available at www.cewh-cesf.ca/healthreform/default.html
- Heather Goodman, Home Care and Women: An Annotated Bibliography of CEWHP Home Care Documents, CEWH, 2001. Available at www.cewh-cesf.ca/healthreform/default.html

Other Publications:

- Pat Armstrong and Olga Kits, *One Hundred Years of Caregiving*, Law Commission of Canada, 2001. Available at www.cewh-cesf.ca/healthreform/default.html
- Marika Morris et al., *The Changing Nature of Home Care and Its Impact on Women's Vulnerability to Poverty*, Status of Women Canada, The Canadian Research Institute for the Advancement of Women, 1999. Available at www.swc-cfc.gc.ca/pubs/0662280857/index_e.html

Organizations:

- *The Canadian Home Care Association*
www.cdnhomecare.on.ca/
- *The Canadian Caregiver Coalition*
www.ccc-ccan.ca

Who We Are and What We Do

The National Coordinating Group on Health Care Reform and Women came together in 1998 as a collaborative group of the Centres of Excellence for Women's Health, and the Canadian Women's Health Network, with support from the Women's Health Bureau. The Group's mandate is to investigate the impact of health care reform on women as providers, decision makers and users of the health care system. We aim to increase awareness and understanding of the impact of health care reform on women and wish to become involved in the promotion of such activities.

ordering information

Copies of this booklet can be downloaded from:

www.cewh-cesf.ca/healthreform/default.html or can be ordered free from

the Canadian Women's Health Network (**cwhn@cwhn.ca** or **1-888-818-9172, TTY 1-866-694-6367**).

Bulk orders are available; a shipping fee may be required. Permission to duplicate is granted provided credit is given and the materials are made available free of charge. Également disponible en français.

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[Union bug]



*“When the health care system is cut back women get hit with a triple whammy. **First**, women tend to be the health care workers who are losing their jobs or are being run off their feet because of understaffing. **Second**, women and their children tend to be the heaviest users of the health care system. **Finally**, women have to pick up the slack when the state no longer funds health care services.”*

Susan Dusel, “Government puts the brakes on women’s movement”
Network of Saskatchewan Women,
Vol. 4, No. 7, 1987, p. 4