

The Family Caregiving Legal Research Project¹

I. An Introduction to Family Caregiving

Taking care of dependent or vulnerable adult family members, rather than contracting the work out to third parties outside the family, is the norm in many cultures. This practice is known as family or informal caregiving. Family caregivers look after aging parents, children with disabilities, and people coping with mental health issues, addictions and chronic illnesses. Caregivers manage medical care, assist with intensely intimate elements of personal care, and provide a range of services including emotional support, meals, housework and mobility assistance – all tailored to the particular needs of a loved one and organised around the other demands work, family and community impose on a caregiver's time and energy.

Family caregiving encompasses different kinds of relationships. Some caregiving relationships are life-long, as may be the case with children with disabilities. Other recipients of care have fluctuating needs, with care increasing during periods of poorer health and becoming minimal when an illness is in remission. Post-surgical care may be intense but temporary. In contrast, some degenerative conditions are characterized by increasing needs such that a caregiver may be providing care on a full-time basis for many years.

While there is great diversity in the amount of time caregivers spend in caregiving, and the nature of caregiving relationships, caregivers face substantial demands on their time. Duxbury, Higgins and Shroeder's recent study of employed caregivers who maintain full-time positions found that "the majority of caregivers 'work' the equivalent of two full time jobs: they spend an average of 36.5 hours per week in paid employment and 34.4 hours per week in caregiving".² Balancing paid work and unpaid caregiving in a healthy manner thus presents an enormous personal challenge. The potential work-related consequences of caregiving are significant, including a reduction in employment income, pensionable earnings and opportunities for career development, as well as terminations and resignations.

However, the challenge of balancing work and care is arguably not only the problem of the individual worker or a family. Unpaid family caregiving forms a key social institution, representing a significant component of Canada's publicly-funded health care system. Community care has become an increasingly large aspect of the Canadian long-term care strategy as a function of de-institutionalization of aspects of health care service delivery and a rapidly aging population.

¹ By Krista James, Staff Lawyer, British Columbia Law Institute, Canadian Centre for Elder Law. This paper presents initial research and findings of the British Columbia Law Institute and the Canadian Centre for Elder Law in the area of supporting family caregivers who are trying to balance paid work and unpaid caregiving. The purpose of this article is to raise awareness of the issues and this project and to stimulate discussion. We welcome your comments at familycare@bcli.org or you may contact Krista James, the project coordinator, at 604-822-0564. However, it is too soon in our process to present conclusions. The final report of the Family Caregiving Legal Research Project will be available online in February 2010 at <http://www.bcli.org/ccel/projects/family-caregiving>.

² Linda Duxbury, Christopher Higgins & Bonnie Shroeder, *Balancing Paid Work and Care Responsibilities: A Closer Look at Family Caregivers in Canada*, (2009) at 9.

The question of how the costs of caregiving ought to be distributed between individuals, family, employers and the state also raises issues of gender equality, for in spite of women's comparable rates of participation in the labour force, care remains overwhelmingly the work of women.³ A number of features of contemporary families further exacerbate this disparity: high rates of divorce mean women are providing care with less support from the family infrastructure; lower rates of fertility concentrate the care of an increasing community of care recipients on the resources of fewer caregivers; and delayed parenting means women are increasingly balancing caring for children and parents during the same phase of their lives.

Family caregiving in an aging population also raises a problem for labour force participation. As Terrence Hensley explains:

There was a time when a matter, such as work-life balance, would have been considered a private concern for families to work out. But when the economy, as well as families' ability to live at prevailing community standards, depends on the supply of two workers per family, and when the fertility rate continues to drop, private risks tend to be defined as public crisis.⁴

It is in response to these socio-demographic concerns that the British Columbia Law Institute and the Canadian Centre for Elder Law embarked on the Family Caregiving Legal Research Project. This project examines how the laws of British Columbia currently respond to the needs of working caregivers and explores how legislation could be revised to be more supportive of family caregiving. This project is comparative: although the focus is BC, we consider the circumstances in other Canadian jurisdictions and also in countries with a similar legal structure. The purpose of the comparative approach is to investigate creative solutions to the challenge of supporting the growing community of caregivers in BC.

As part of our assessment of caregiver needs and options for reform this project also included: an electronic survey of BC family caregivers; and a telephone survey of a select group of employers, chosen because they had been identified, through other surveys, as leaders in supporting employers to balance work and family responsibilities. At the time of writing, the research aspect of the Family Caregiving Legal Research Project is largely complete and we are currently assessing the options for reform. The full project report, including the results of our surveys, will be assessable online in February 2010 at <http://www.bcli.org/ccel/projects/family-caregiving>. This article presents some of the early findings of the Family Caregiving Legal Research Project in order to raise awareness of the issues, stimulate discussion, and solicit input on reform options.

II. Broad Overview of the Laws impacting Family Caregiving

There is no single law in BC or Canada that addresses the circumstances of working caregivers. Rather, this area is impacted by legal provisions found in employment and labour law, human rights, pensions, tax policy and health law. Existing legal recognition of the

³ Pyper, Wendy, "Balancing Career and Care", *Perspectives on Labour and Income*, Statistics Canada Catalogue no. 74-001-XIE), (November, 2006), online: <<http://www.statcan.ca/english/freepub/74-001=XIE/0020474-001-XIE.pdf>>.

⁴ Terrance Hunsley, "Informal Caregivers: Balancing Work and Life Responsibilities", (2006) 8(3) *Horizons* 3 at 9.

circumstances of family caregivers falls into roughly three categories: (a) employment leave provisions; (b) measures that offset income loss; and (c) workplace family responsibilities accommodation and workplace flexibility.

A. Employment Leave Provisions

Under the British Columbia *Employment Standards Act*,⁵ eligible employees are entitled to five days unpaid family responsibility leave to address the care needs of children and other immediate family members (s.52), and eight weeks unpaid compassionate care leave to provide end-of-life care to family members (s.52.1), the latter of which also may also trigger entitlement to six weeks of employment insurance benefits. Saskatchewan is the only Canadian jurisdiction that provides workers with job protection for more than two weeks in respect of caregiving where there is no risk of immanent death: the *Labour Standards Act* provides for 12 weeks of unpaid leave due to the serious illness of a family member, and additional leave if the worker is entitled to Employment Insurance or Workers Compensation Benefits.⁶ Our review of employment leave legislation identifies BC and Canada as leaders in providing workers with income replacement for end-of-life caregiving, as well as maternity and parental leave benefits, but providing little recognition of other forms of family caregiving.

B. Measures that Offset Income Loss

Measures to offset income loss include tax incentives, as well as pensions and direct stipends or wages paid to the caregiver in recognition of caregiving labour. This is an area Canada has not explored significantly. The last ten years has witnessed a proliferation of studies on the needs of caregivers, all of which highlight the financial strain associated with caregiving and indicate a need for reform to address the short and long term income security of caregivers; however, few resources exist in BC to support family caregivers.

(i) Income Tax Measures

The tax system currently includes a number of tax credits that are available to taxpayers who reside with family members who have a physical or mental disability and are dependent on the taxpayer for financial support. A major problem with this approach is that due to non-refundability of existing tax measures – including the Caregiver Tax Credit⁷ – are accessible only to higher income earners. One of the other problematic features from the perspective of caregiver policy is that eligibility is linked to financial dependency rather than caregiving labour.

⁵ *Employment Standards Act*, R.S.B.C. 1996, c.113.

⁶ *Labour Standards Act*, R.S.S. 1978, c. L-1, s. 44.2(1)(b).

⁷ *Income Tax Act*, R.S.C. 1985 (5th Supp.), c.1, s. 118(1)(c.1). The Act now refers to this provision as the in-home case of a relative provision.

(ii) Payments to Caregivers

In BC, payments to caregivers are only possible indirectly and by way of exceptions to health policy. The Choice in Supports for Independent Living program (CSIL)⁸ provides eligible people with disabilities with access to funds that they may spend at their discretion on their own care; however, payments to caregivers who are also family relations is permitted only in very limited circumstances. No BC program provides direct payments to family caregivers in recognition of their labour.

(iii) Pension Security

Finally, public pension measures that take into account the impact of caregiving activity on earnings and pension security exclusively address the care of young children. The Child-Rearing Provision permits a parent to exclude years during which she was not engaged in paid employment in the determination of Canada Pension Plan entitlement.⁹ This measure allows an individual to discount up to the first seven years of a child's life. There is no parallel measure with respect to other forms of caregiving. In BC there is also no caregiver-specific pension to supplement the income of older caregivers who have left the workforce permanently, and often prematurely, to become full-time caregivers. Caregivers who reduce their earnings in order to provide caregiving possess no pension security protection, and thus face poverty during their "retirement" years.

C. Family Responsibilities Accommodation and Workplace Flexibility

Family responsibilities accommodation in the workplace is a somewhat uncertain area of law in BC and the rest of Canada. Subject to the prohibition against discrimination against employees in the terms and conditions of employment contained within the BC *Human Rights Code*, there is no employee right to work flexibility in relation to family caregiving obligations in this province. Accommodation of caregiving responsibilities is generally at the discretion of employers, unless the employee can successfully characterize the employer's facially-neutral rule or rejection of a workplace flexibility request as adverse affect discrimination. The leading BC case on when a conflict between workplace and family responsibilities will give rise to discrimination has established a test that is very difficult for employees to meet. The employee must establish that "a change in a term, or condition of employment, imposed by the employer results in serious interference with a substantial parental or other family duty."¹⁰ Although there exist very few cases that deal with the caregiving of adult family members – most cases pertain to childcare – recent case law indicates a pattern of controlling the floodgates by limiting human rights protection to extraordinary, not common, caregiving responsibilities. What amounts to an uncommon caregiving obligation is unclear at this time.

⁸ Ministry of Health, "Community Care Services", online: <<http://www.health.gov.bc.ca/hcc/csil.html>>.

⁹ *Canada Pension Plan* R.S.C. 1985, c. C-8, s.48(2).

¹⁰ *H.S.A.B.C. v. Campbell River & North Island Transition Society*, 127 L.A.C. (4th) 1 (B.C.C.A.).

The Current Legislative Regime At a Glance

LEGISLATION	BENEFIT	DETAILS	LIMITATIONS
<i>Employment Standards Act, s.52</i>	Family Responsibility Leave	5 days unpaid leave per year May take 1 day at a time	* Many types of workers are not covered by the Act * Narrow definition of family excludes some caregiving relationships *length is inadequate
<i>Employment Standards Act, s.52.1</i>	Compassionate Care Leave	8 weeks unpaid leave per year to care for a family member with a serious medical condition if a significant risk of death within 26 weeks	* Many types of workers are not covered by the Act * Limited to end-of-life caregiving *length of leave is inadequate
<i>Employment Insurance Act</i>	Compassionate Care Leave Benefits	6 weeks of income replacement benefits during the 26 week window of caregiving	* Must be eligible for EI Excludes many work arrangements (eg., self-employed) * Benefit amount is tied to employment earnings so value is based on pre-leave earnings not the value of care
<i>Human Rights Code s. 13(1)</i>	Protection against discrimination in a term or condition of employment (based on family status ground)	An employer's unwillingness to allow an employee to change working arrangements in order to balance work and care may amount to discrimination. An employer may be required to accommodate schedule or other changes.	* Case law has resulted in a strict test * Must frame employer rule as discrimination * Complaint model (cost, time, litigation) * Seems to apply only to extraordinary obligations
<i>Income Tax Act, s.118(1)(c.1)</i>	Caregiver Tax Credit (In-home Care of a Relative Credit)	May deduct \$605 from income tax payable (amount changes over the years)	*Care-receiver must reside with caregiver in a separate, self-contained residence * Excludes care of friends * Amount of credit is low in relation to value of caregiving labour * Non-refundable, regressive measure * Eligibility is tied to financial dependency not caregiving labour

III. Impact of Existing Laws on Family Caregivers

The impact of legislation on unpaid family caregivers is best illustrated in relation to portraits of caregivers. The following three stories are representative of the breadth of employment related challenges caregivers encounter.

These stories are fictitious in the sense that they are fabricated composites crafted from reviewing literature on family caregiving. In particular, they are informed by responses to our caregiver survey. Many respondents took the time to tell their own story of struggling to balance work and care, and this information has greatly informed our characterization of the issues and our assessment of BC legislation and policy. However, each of these caregiver stories is an invention. These stories by no means represent caregivers in all their diversity, and the full report works with additional stories in order to capture a greater cross-section of problems. However, for the purposes of this report, these three stories should highlight a number of deficiencies within the existing legislation and policy as well as ensure that our thinking remains grounded in the experience of caregiving.

A. Grace's Story

Grace and her ex-husband have two children. Both are now in high school. Until recently, Grace stayed home in order to spend more time with her children and take responsibility for most of the family's domestic responsibilities. This decision made economic sense for the family, as Grace's income as a secretary was significantly less than her ex-husband's business income, and the cost of child care remained high in relation to her employment income. The couple is now divorced and Grace is supporting the family through a combination of employment income and child support, the latter of which will only continue while the children remain in school. Grace is an only child, and her aging widowed mother has significant health problems associated with a back injury from which she never fully recovered. Her mother experiences chronic pain associated with sciatica and decreasing mobility. Her mother's health has recently worsened such that Grace spends more and more time helping her mother with appointments, meals and other household tasks, and increasing amounts of time driving back and forth between her home and her mother's apartment. Finally, after only two years of less than full-time employment, Grace is forced to cut back on her hours of work. There are simply not enough hours in the day for taking care of her children and her mother as well as full-time employment.

B. Sunita's Story

Sunita is a unionized employee working in health care. She works a shift schedule set out in her collective agreement: a rotation that includes twelve hour shifts and frequent overnights. Recently her father-in-law suffered a stroke, resulting in partial paralysis, and requiring administration of medication at home as well as ongoing accompaniment to medical and rehabilitation appointments. He has intense, long-term caregiving needs. Although the man has many children, the family decided he should live with Sunita, who has nursing skills. Sunita requested a one month paid leave to assist her to get father-in-law settled into her

home, onto a new routine, and stabilized on medication. Her employer denied her request for a paid compassionate leave and is considering granting her an unpaid leave. In terms of longer term adjustments, Sunita’s employer has denied Sunita’s request for a set schedule of shorter shifts that excludes evenings. Sunita thinks this modification in her hours of work is necessary because her father-in-law is at greatest risk of respiration problems when he is sleeping or lying down. Shift work that includes evenings has become problematic, but there are very few positions in her bargaining unit that are not associated with rotations that include nights.

C. Ingrid’s Story

Ingrid is a single parent. She lives alone with her daughter, who has Down’s Syndrome, and their primary ongoing source of income over the years has been provincial income assistance (welfare) and tax benefits (child tax benefits). Like many parents of children with disabilities, Ingrid was terminated from employment positions many times as a result of work disruptions associated with responding to her daughter’s care needs. Ingrid earns irregular income providing childcare and housework, receiving income assistance some months. Her daughter is now an adult but she continues to require ongoing support from her mother such that Ingrid cannot work traditional full-time hours. Ingrid is looking for part-time flexible work that will allow her to continue to be there for her daughter when needed and finding it challenging to locate suitable work. As a low-income caregiver, who pays very little if any income tax, many tax measures are not helpful to Ingrid.

Summary of the Circumstances of our three Caregivers

CAREGIVER	CAREGIVING RELATIONSHIP	EMPLOYMENT CIRCUMSTANCES
Grace	Divorced woman caring for both school-aged children and aging mother. Long-term caregiving required for her mother.	Works part-time due to caregiving responsibilities. Short-term work history: out of the paid work force until her divorce.
Sunita	Caring for her father-in-law following a stroke. Likely long-term care.	Unionized employee working a full-time rotation that includes nights. Requires schedule changes to maintain caregiving.
Ingrid	Single, low-income parent of an adult child with a disability. Long-term caregiving needs.	Income is a mix of welfare and occasional part-time work in childcare and housecleaning.

The above stories demonstrate some of the problems with the current legislative regime. Sunita would benefit from a paid leave; however, her father's health condition does not trigger eligibility to Compassionate Care Leave. Although the Canadian Compassionate Care leave program characterizes Canada as an international leader in palliative and end-of-life family caregiving, provincial and federal employment standards and employment insurance legislation provide no recognition of economic consequences of ongoing caregiving on the worker. In BC, family responsibility leave, allowing workers to take up to five days off work per year, falls far short from the reality of the demands imposed by most caregiving relationships.

Sunita and Ingrid require accommodation of their caregiving obligations by their employer (potential employer in the case of Ingrid) in order to effectively balance work and care. Both of them foresee long-term caregiving needs on the part of the family member for whom they provide care. As a result of this challenge, Ingrid is only periodically employed. Sunita must negotiate alternative working arrangements and may have to find alternative employment if her employer and her union are not supportive. No law exists to require an employer to consider flexible working arrangements. These workers would have to pursue their right to accommodation via a human rights argument. Given the state of the law, it is not clear that either of them would be successful.

The financial consequences of caregiving are significant for most caregivers. This is particularly the case for Grace, who must support and care for school-aged children and her mother simultaneously. It is also the case for Ingrid, who has been unable to secure ongoing employment given her child's significant care needs, and as a result has largely relied on welfare as a means of support. Due to non-refundability, tax measures are effectively unavailable to Ingrid, whose income is so low that she does not pay taxes, and Grace's tax payable may also be too low.

The impact of family caregiving on Grace and Ingrid is that they face the prospect of poverty in their old age. Given Ingrid's patchy work history, she will likely be completely reliant on publicly funded old age security, thereby surviving on little more than provincial welfare levels during her retirement years. Grace will experience reduced Canada Pension Plan benefits, due to poor contributions caused by reductions in wage and hours of employment. The child-rearing drop out provision - the only pensions measure that addresses caregiving labour - is inadequate to address her circumstances, as her caregiving encompasses significantly more than the first seven years of a child's life. She will likely benefit from pension credit splitting with respect to some of the years of her marriage. The CPP legislation does not contain a measure that addresses her years of caregiving for her mother.

IV. Results of our International Research

Our international research reveals alternative approaches to the problem of supporting family caregiving labour. Here are few examples of what is happening in other jurisdictions.

JURISDICTION	BENEFIT	DETAILS
Saskatchewan <i>Labour Standards Act</i> , R.S.S. 1978, c. L-1, s. 44.2(1)(b)	Serious Illness or Injury Leave	12 weeks unpaid leave 16 weeks compassionate care leave
Manitoba <i>Income Tax Act</i> , S.M. 1988, c. I10, s. 511(1)	Primary Caregiver Tax Credit	Refundable tax credit for caregivers who provide significant care. Amount: up to 1,020 per care-recipient. Can receive for up to 3 care-recipients.
Nova Scotia	Allowance to Aid Caregivers	\$400 monthly benefit for caregivers who provide 20 hours or more of care per week.
United Kingdom <i>Flexible Working (Eligibility, Complaints and Remedies) (Amendment) Regulation 2006</i> , S.I. 2006/3314 & New Zealand <i>Employment Relations (Flexible Working Arrangements) Amendment Act 2007</i> (N.Z.), 2007/105, s.69AA	Work flexibility legislation	Employer is required to consider requests to modify terms of employment such as hours of work and location where the change is required to for caregiving. Employer discretion. Act sets out broad business grounds for refusal and there is no right of appeal.
New Zealand <i>Human Rights Act 1993</i> (N.Z.), s.21(1)(l)	Discrimination on family status	Defined to include care of children and other dependents
Australia <i>Anti-Discrimination Act 1977</i> (NSW), No. 48, PART 4B; <i>Equal Opportunity Act 1995</i> (Vic); <i>Sex Discrimination Act 1984</i> (ACT) s.7A	Prohibits discrimination on the basis of family responsibilities or carer status	Prohibits adverse affect discrimination family against caregivers (a neutral rule that creates a barrier for caregivers). An employer must accommodate an employee's responsibilities as caregiver.

Netherlands <i>Work and Care Act</i>	Career interruption leave	6 months leave for educational or caregiving purposes. Income replacement at 70% by the Government if the employer is able to replace the person on leave with someone otherwise unemployed.
Sweden <i>Care for the Elderly</i> legislation, 1990	Carers' Allowance	The state pays caregivers providing extraordinarily burdensome care a taxable salary comparable to an average wage.
Norway	Pension credits	The state makes pension plan contributions on behalf of caregivers performing more than 22 hours of care per week for a 6-month period.

V. Options for Reform

As the Family Caregiving Legal Research Project remains a work-in-progress, it is not possible to present final recommendations at this time. However, here are some options for reform that we are considering.

A. Employment Leave

Compassionate care leave benefits could be expanded to include other forms of adult caregiving, and the duration of benefits could be lengthened such that part of the leave would trigger income replacement benefits. A number of reports including the Final Report of the Special Senate Committee on Aging,¹¹ the Romanow Report on Health Care,¹² and the Arthurs Report into federal labour standards¹³ recommend financial support for non end-of-

¹¹ Special Senate Committee on Aging, *Canada's Aging Population: Seizing the Opportunity* (Ottawa: 2009) at 117 and 127.

¹² Commission on the Future of Health Care in Canada, *Building on Values: The Future of Health Care in Canada*, by Roy J. Romanow, (Ottawa, 2002) at 183, online: <<http://publications.gc.ca/pub?id=237274&sl=0>>.

¹³ Federal Labour Standards Review Commission, *Fairness at Work: Federal Labour Standards for the 21st Century* (Ottawa: Human Resources and Skills Development Canada, 2006), online: <http://www.hrsdc.gc.ca/eng/labour/employment_standards/fls/index.shtml>

life caregiving. The Romanow Report pre-dates the Compassionate Care Leave Program, but the other two reports recommend the program be expanded to include the caregiving of family members with serious illnesses. One of the questions that remains, is “what is the appropriate length of paid and unpaid leave?”

The following framework illustrates one approach to this problem:

- Amend the requirements for eligibility to compassionate care leave under the *Employment Standards Act* to include circumstances where a family member requires time off work to care for a family member who suffers from a serious illness or other serious health condition, regardless of the likelihood of death.
- Similarly amend the requirements for eligibility to compassionate care leave benefits under the *Employment Insurance Act*.
- Extend the duration of compassionate care leave under the *Employment Standards Act* to one year, in order to parallel the duration of leave available in the case of the birth of a child, subject to a requirement to periodically confirm the ongoing serious nature of the condition, for example, every three months.
- Extend the period of entitlement to benefits under the compassionate care leave program to up to 16 weeks, using Saskatchewan as a model for reform.

Another option is to expand the rules of entitlement under the *Employment Insurance Act* such that self-employed individuals would be entitled to compassionate leave care benefits.

B. Accommodation of Caregiving Responsibilities in the Workplace

Consistent with recent amendments to employment legislation in the U.K. and New Zealand, the BC *Employment Standards Act* could be amended to create a right to request variations in the location and hours of work, including changes to part-time status, where an employee requires these changes in order to manage family caregiving obligations. This the approach recommended by the Arthurs Report.

C. Income Replacement

In order to create a tax credit that is accessible to low-income people and properly targets individuals who provide caregiving labour, the federal government could create a refundable tax credit that references the provision of caregiving labour as an eligibility criterion, possibly modelled on the new Manitoba legislation.

The provincial and federal governments may explore income replacement for low-income family caregivers either through attaching greater dollar value to a refundable caregiver tax credit or the creation of a direct caregiver allowance payable into the typical years of retirement and during the years of the life course when a caregiving maintains paid

employment. The amount of the payment becomes an issue. Existing allowances range from the \$400 allowance recently introduced in Nova Scotia to the caregiver wages paid by the governments of Norway and Sweden.

D. Pension Security

In recognition of the impact of family caregiving on pension security the *Canada Pension Plan Act* could be amended in the following two respects:

- to include a drop-out provision parallel to the Child-Rearing Provision that would be applicable to all years of full-time family caregiving. This approach would build on the existing Canadian approach.
- to include a commitment from the federal government to top-up the contributions made on behalf of family caregivers where reduced hours of employment would otherwise result in a reduction in contributions and consequent pension entitlement. The approach would target those caregivers who lack a stable period of higher earnings because a lifetime of caregiving has prevented full-time employment.

VI. Conclusion

Given recent social and demographic changes, it is timely to consider law reform measures that will support family caregivers to balance work and caregiving responsibilities, and provide greater recognition of the social value of unpaid family caregiving labour. The Family Caregiving Legal Research Project takes on this challenge. Supporting caregivers requires a comprehensive strategy encompassing tax law, pensions, health policy, human rights and employment law. The question of how the costs of our aging population should be distributed between and amongst family, community, employers and the state raises complex public policy issues based in notions of paid and unpaid work. Historically family caregiving has been constructed as a private issue to be addressed by individuals within the family sphere. This approach may no longer be tenable.