The Day We Stop Caring
Caregiving for the Future

Adalsteinn Brown
Breakfast With The Chiefs
13-05-2009
So how bad is it going to be?
The Demographics Of Canadian Caregivers Today

Gender
- Female: 54%
- Male: 46%

Age
- 18-24: 15%
- 25-34: 28%
- 35-44: 23%
- 45-54: 18%
- 55-64: 9%
- 65+: 7%

Income
- <$25K: 5%
- $25-50K: 17%
- $50-$75K: 25%
- $75-$100K: 26%
- >$100K: 26%

Deloitte Canadian Health Consumer Survey 2009
No. Of Persons Cared For By Canadian Caregivers
- 8% Are Caring For 3+ Persons

Seniors Care For Their Spouses And Close Friends


<table>
<thead>
<tr>
<th>Care was received by:</th>
<th>Caregivers Aged 45-64</th>
<th>Caregivers Aged 65+</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Spouse/partner</td>
<td>24,805</td>
<td>1.4</td>
</tr>
<tr>
<td>Father</td>
<td>236,284</td>
<td>13.4</td>
</tr>
<tr>
<td>Mother</td>
<td>732,406</td>
<td>41.6</td>
</tr>
<tr>
<td>Brother</td>
<td>7,928</td>
<td>0.5</td>
</tr>
<tr>
<td>Sister</td>
<td>11,435</td>
<td>0.6</td>
</tr>
<tr>
<td>Son/daughter/grandson/granddaughter/son- or daughter-in-law</td>
<td>3,136</td>
<td>0.2</td>
</tr>
<tr>
<td>Grandfather or grandmother</td>
<td>12,887</td>
<td>0.7</td>
</tr>
<tr>
<td>Father-in-law</td>
<td>82,983</td>
<td>4.7</td>
</tr>
<tr>
<td>Mother-in-law</td>
<td>218,024</td>
<td>12.4</td>
</tr>
<tr>
<td>Brother-in-law</td>
<td>9,824</td>
<td>0.6</td>
</tr>
<tr>
<td>Sister-in-law</td>
<td>5,410</td>
<td>0.3</td>
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<tr>
<td>Uncle</td>
<td>16,431</td>
<td>0.9</td>
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<tr>
<td>Aunt</td>
<td>50,473</td>
<td>2.9</td>
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<tr>
<td>Cousin</td>
<td>9,034</td>
<td>0.5</td>
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<tr>
<td>Close friend</td>
<td>161,053</td>
<td>9.2</td>
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<tr>
<td>Neighbour</td>
<td>144,338</td>
<td>8.2</td>
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<tr>
<td>Other</td>
<td>32,927</td>
<td>1.9</td>
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<tr>
<td>Number of Caregivers</td>
<td>1,759,378</td>
<td>100.0</td>
</tr>
</tbody>
</table>

* Caregivers could provide care to more than one care receiver
The Burden Of Canadian Caregivers Is High . . .

- 10% of Canadians report having a family member who requires constant care from a family caregiver
- 27% of Ontario families have been providing constant care for over 2 years
- 1 in 6 in Ontario report constant care requirements to have a major impact on the ability to earn family income
- 1 in 4 caregivers has no help; 1 in 4 have paid help; 61% need more help
- The average caregiver has spent 20h/week caring for 4 years; ¼ spent 40h/week
- 32% also have children under 18 living at home
- 15% of caregivers describe their quality of life as poor

Deloitte Canadian Health Consumer Survey 2009
Leading To A High Level Of Physical And Mental Stress

- 46% experienced stress;

- 14% experienced physical discomfort or physical pain;

- 15% report that people they care for are verbally or physically abusive;

- 19% were frail, disabled or needed care themselves

Ontario’s Projection Of The Aging Population Is Worrying …

Sources: Statistics Canada 1985-2004, and Ontario Ministry of Finance projections
And the cross-over is only a few years away

Number of children (0 to 14 years) and persons aged 65 years and over observed (1981 to 2005) and projected (2006 to 2056) according to six scenarios, Canada

Traditional Support Networks Are Disappearing

- Nuclear families decreased by 18%
- 3x as many single person households, as households of 5 persons or more
- 51.5% of the population was not married in 2006, outnumbering married population for the first time since census began
- 42.7% of households had no children, for the first time, more than households with children
- 1.5 million single parent families, i.e. 1 in 4 families with children is headed by a single parent, up 8%
- Single parent families headed by men increased by 14.6%, more than 3x single parent families headed by women

Statistics Canada. 2006 Census.
The Dependency Ratio In Canada Will Balloon

## How Much Should Caregiving Cost Us Today?

<table>
<thead>
<tr>
<th>Annual costs at hourly market rates for Homemakers</th>
<th>Annual costs at hourly market rates by Type of Provider</th>
</tr>
</thead>
<tbody>
<tr>
<td>$24,155,528,240</td>
<td>$31,298,054,777</td>
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</table>

Cost of caregiving for Canadian Seniors 65+ extrapolated to 2007

How Much Will It Cost Canadian Caregivers?

Annual Costs of Caregiving for Seniors Aged 65+ v.s. Population of Potential Caregivers Aged 15-64 Extrapolated to 2030

Medical Success Leads To New Care Challenge

- Better Diagnoses
- Earlier Intervention
- Medical Advancements
- Environmental Factors

Increased Children Survival Rates

1.6% of young children have Disabling Conditions

Medical Success Leads To New Care Challenge

Better Diagnoses  
Earlier Intervention  
Medical Advancements  
Environmental Factors  

Increased Children Survival Rates  

1.6% of young children have Disabling Conditions

We Will Be Caring For More Children In The Future

- Very Severe: 42%
- Mild to Moderate: 57%
- Others: 1%

Is it time to talk about caring?
Canadians Stand Out On Caregiving

Web Search Volume: caregiver vs. caregivers vs. carer...
Worldwide, 2004 - present
Categories: Health, Lifestyles, Local, Games, Society, Finance & Insurance

Regional interest

1. Philippines
2. Fiji
3. Nepal
4. Canada
5. Jamaica
6. United States
7. New Zealand
8. Singapore
9. United Arab Emirates
10. Kenya
Ontarians Lead Canada In Their Interest

Web Search Volume: caregiver+caregivers+caregiving
Canada, 2004 - present
Categories: Health (25-50%), Lifestyles (10-25%), Local (0-10%), Society (0-10%), Games (0-10%), more...

Interest over time

Regional Interest for caregiver+caregivers+caregiving
1. Ontario 100
2. British Columbia 99
3. Alberta 90
4. Newfoundland 85
5. Nova Scotia 64
6. Saskatchewan 59
7. Manitoba 53
8. New Brunswick 41
9. Quebec 20
10. Yukon Territory 0

News headlines: Show Hide
Learn what these numbers mean

Search volume index
0 100

Zoom Out
Health Human Resources Are Our Top Issue

<table>
<thead>
<tr>
<th>Australia</th>
<th>Canada</th>
<th>New Zealand</th>
<th>U.K.</th>
<th>U.S.</th>
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<td>carer jobs</td>
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<td>live in caregiver</td>
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<td>carrie the caregiver</td>
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Carrie the Caregiver is an exciting casual game combining arcade action with thoughtful and elegant puzzle design.
Top Keywords On Top 100 Caregiver-related Organizations Websites According To Google
Top Keywords on Top 100 Caregiver-related Blogs According To Google
Notice the difference in the language?
Long-Range Scenario Planning Can Help To Explore Complex Issues Like Caregiving

- **Trends**: 30 health leaders, experts and researchers helped identify the most important trends.
- **Implications**: 120 health leaders, experts and informants identify key implications.
- **Scenarios**: 150 health leaders, experts and informants identify strategic responses to each scenario.
- **Robust Themes**: 300 health leaders, experts and informants identify and reviewed robust themes that matter in all scenarios.
- **Policy Options and Leading Indicators**: Jul 2009
Caregivers in 2033

Uncertainties about the future can pose as opportunities and risks.

- Aging Boomers: Family Or Government Responsibility?
- Litigious Policy Developments?
- Technology: Hero Or Villain?
- New Work Environments?
- Fortunes: A Prosperous Or Struggling Ontario?
- Natural Resources: Competition Or Cooperation?
- Gaps And Divides: Economic And Geographic?
- New Health And Social Funding And Delivery Models?
- A World Adapted To Climate Change?
- New Forms Of Political Voice And Advocacy?
In October 120 participants helped identify the most important implications of the long-range trends.
* downloading preparation (training, equipment)
  * community vs. state
  * balance of hospital vs. community (services)
  * coordination across sectors/communities

* balance b/n work and gov’t (who’s Responsible for caregiving resp.)
  * obligation or incentive
  * economics vs. values
  * who pays & forms of payment

* sentimentalizing “family”
  * Caring society vs. consuming society
  * who cares if no one cares (state, hospital, community, social network)
  * quality vs. quantity of care
  * end of life prolonging & at what cost

* what’s the dominant value set
  * generational difference
  * choice vs. responsibility changing family structures
  * families & social networks
  * independence vs. interdependence
  * cultural duties, balance

* enabling technology
  * technology as enabling not replacing
  * technology as fixer vs. cost/drain

* lack of understanding
  * role of legal interventions (fraud)
* balance b/n work and gov't (who's Responsible for caregiving resp.)
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In November, 150 Informants and Experts discussed responses that will allow each of the four scenarios (representing plausible, not preferred futures) to be viable.

- **Caring from a Distance**
- **Designed for Living**
- **Appreciating Care**
- **Neighbour’s Keeper**
<table>
<thead>
<tr>
<th>Adapting to Changing Families &amp; Communities</th>
<th>Building on Social Networks</th>
<th>Valuing Caregiving</th>
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<tbody>
<tr>
<td>Improving Care with Technology</td>
<td>Caring-About-Caregivers</td>
<td>Accessing Information</td>
</tr>
<tr>
<td>Promoting Choice for Support</td>
<td>Competing And Caring</td>
<td>Enabling Vulnerable Populations</td>
</tr>
</tbody>
</table>
#1 Redefine “Caregivers”  
#2 Protect care recipients  
#3 Leverage Neighbourhood Hubs  
#4 Incubate Social Cooperatives  
#5 Leverage Social Networking  
#6 Create “Good Neighbours” Law  
#7 Promote Caregivers Voice  
#8 Promote Awareness of Caregivers  
#9 Expand on “Best Employer” Criteria  
#10 Reanimate Volunteerism  
#11 Accelerate Technology-enabled Caregiving  
#12 Reduce Information Deficit  
#13 Enable Navigation  
#14 Provide Caregiver Education  
#15 Provide Caregiver Assessment  
#16 Provide Choice of Self-Directed Care  
#17 Invest in Stable Caregiver Support  
#18 Balance “Triple Bottom Line”  
#19 Create Flexible/Portable Hubs  
#20 Begin Gov-Business Dialogue  
#21 Promote Employment Benefits and Protection  
#22 Provide “Universal” Benefits and Protections  
#23 Strengthen services for the Vulnerable
<table>
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<th>Strategic Options by Theme</th>
<th>Themes Ranked by Priority</th>
<th>Themes Ranked by Public Policy Priority</th>
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<tr>
<td>1. Redefine “Caregivers”</td>
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<td>1</td>
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<tr>
<td>2. Protect Care Recipients</td>
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<tr>
<td>3. Leverage Neighbourhood Hubs</td>
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<td>13. Enable Navigation</td>
<td>1</td>
<td>4</td>
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<td>14. Provide Caregiver Education</td>
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<tr>
<td>23. Strengthen services for the vulnerable</td>
<td>6</td>
<td>3</td>
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</tbody>
</table>
Theme 1

Adapting To Our Changing Families And Communities

#1 Reconstructing the Policy Definition of “Caregiver”

#2 Ensuring a System of Protection for Care Recipients
Theme 2

Paying Attention To Changing Forms Of Social Connection And Building On Social Networks

#3 Strategic Investment in Neighbourhood “Hubs”

#4 Strategic Investment in Social Cooperatives

#5 Building a System for Social Networking

#6 Implementing “Good Neighbours” Legislation
Ontarians Are Focused On Neighbourhood

Web Search Volume: Ontario (Canada) vs. Australia vs. United Kingdom...
for neighborhood + neighbourhood, 2004 - present
Theme 3

Valuing Caregiving

#7 A Public and Political Voice for Informal Caregivers

#8 Strengthening Ontario’s Awareness of the Informal Caregiving Role

#9 Expanding the Meaning of “Best Employer”

#10 Reanimating Volunteerism for the 21st Century
Improving the Scope and Efficiency of Informal Caregiving Through Technology

#11 Stimulating the Development of Technology-Enabled Systems

#12 Using Virtual Technology to Reduce Information Deficit
Canadians Are Looking For Home Care Technology

Web Search Volume: home care technology
Worldwide, 2004 - present
Categories: Health (10-25%), Local (0-10%), Lifestyles (0-10%)

Interest over time

Regional interest for home care technology
1. United States
2. Canada
3. United Kingdom
4. Italy
5. Taiwan
6. Singapore
7. Philippines
8. New Zealand
9. Netherlands
10. India
Theme 5

Timely Access
To Reliable Information

#13 A Structure to Enable System Navigation

#14 A Provincial System of Caregiver Education
Theme 6

Promoting Opportunity And Choice For Support

#15 Creating a Formal Process for Caregiver Assessment

#16 Empowering the Choices of Informal Caregivers through Self-Directed Care

#17 Building a System of Support through Stable and Efficient Investments

#18 Adopting a Triple Bottom Line

#19 Building a System of Support through Flexible and Portable Hubs
“My son may be a quadriplegic but with home-care and assisted living help, he can live independently in our community where he is well-known and loved. Why does he have to make the choice of moving or losing his services?”
Theme 7

Competing And Caring With Flexible Benefits And Supports

#20 Initiating a Government-Business Dialogue for Informal Caregivers

#21 Building Benefits and Employment Protection for Informal Caregivers
“British Telecom has seen annual savings of $375M CDN for its 160,000 employees in 61 countries, of which 81% work flextime and 18,000 are home-based. 99% of employees also return after maternal/parental leave (compared to 47% nationally).”
Ontario Also Focused On Parental Leave

Web Search Volume: Ontario (Canada) vs. Australia vs. United Kingdom...
for parental leave, 2004 - present
Categories: Business, Local, Travel, Society, Lifestyles, Finance & Insurance
Theme 8

Promoting Equity And Enabling Vulnerable Populations

#22 A Provincial Program with ‘Universal’ Benefits and Protections

#23 Strengthening Outreach and ‘Wraparound’ Services for Informal Care Needs of the Vulnerable
“My grandmother mostly spoke Ojibwa. When she was placed in a room with an Italian woman, all she did was cry. If only she could be with other First Nations people…”
Reaching Out To More Caregivers With New Tools
Who Is Twittering About Caregiving?
Outstanding resources for caregivers and health professionals available through the Family Caregiver Alliance

www.caregiver.org

6:47 AM May 9th from web

NotesOnNursing
Amy Berman
What Are They Twittering About?

Guides for grandparents raising grandchildren; kinship care & other relative caregiver resources and links: http://tinyurl.com/csmc2j

12:29 PM May 6th from web

centerforcw
Child Welfare
A National Caregiving Strategy was recommended by the Special Senate Committee On Aging in the April 2009 Final Report to provide a mix of financial support and services for Canadian caregivers.

Japan has proportionately 50% more elders than Ontario, and is helping their seniors use technology to strengthen their social networks.

Australia has caregiver payments and allowances legislation and a powerful voice in Carers Australia, now advocating caregivers rights and income support.
British Telecom has discovered that supporting caregivers is good business – for retention, return to work, and job satisfaction.

Are there opportunities for Ontario’s businesses to join these leadership ranks?

Ontario researchers have discovered how to divert from 25% to 50% of Long-Term Care costs by investing in discretionary and self-directed community-based care.

Ontario has the capacity to use this knowledge now as a Canadian and global leader.
“...Caregiver support is an essential service in our health care system, not merely a ‘top-up’ or ‘nice to have’.”

Shirlee Sharkey, President and CEO,
Saint Elizabeth Health Care

Supporting our carers isn't difficult, disruptive or expensive;
it's plain business sense.

Caroline Waters, Director, People Networks, British Telecoms
(in The Guardian, Carers Week, June 2006)

“These (‘Caring-for-Caregiver’) options cry out for immediate demonstration projects about social co-ops, neighbourhood hubs, self-directed care, new benefits and employment or income protections.”

Judith Maxwell,
Founding President, Canadian Policy Research Network
More Than Half Of The Options Are Net-zero To Low-cost And Are Plausible With Current Resources

<table>
<thead>
<tr>
<th>Low Risks/Costs</th>
<th>Low Risks/Moderate-High Costs</th>
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“The responsibility of caregiving is a social one, with deep connections and dependencies with community, government and business.”

Jane Jensen, Canadian Policy Research Network