

**Dying for Care: Corporate Canada and the
Compassionate Care Benefit**

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Check against delivery

Thank you, Nicholas and good afternoon, everyone.

I'm very pleased to be here today and have the opportunity to speak with an audience that is very different than I'm used to speaking to, about a subject which is not typical of what most CEO's would speak about. I'm here today wearing two hats: one is that of a corporate CEO and the other as a member of the Champion's Council of the Canadian Hospice Palliative Care Association. My subject is one that each of you will likely deal with at some point in your life, and that is: caring for and supporting someone you love during the process of dying. How many of you have experienced this already?

It's a difficult subject for anyone to think about. Most people would rather contemplate filing an income tax return than about their own death or the death of a loved one.

So, why have I chosen a business audience to talk to about this difficult subject and one that, at first glance, seems far removed from the world of work? I have because I am convinced that employers have a key role to play in improving the end-of-life experience. I am also convinced that this is an area where sound business practice and 'doing the right thing' are one and the same.

That's why I'm with you here today.

Let me start with some dry statistics that nonetheless underscore why it is time to discuss this issue openly. Canada's population is greying as more and more baby boomers enter their senior years. Today, around 259,000 Canadians die annually. Within 15 years, that number will increase by 40% to 330,000 deaths per year. Within 25 years, it will increase 65% to more than 425,000 deaths per year.

There's nothing troubling in these numbers – until you consider how prepared we are as a society to care for people at the end of their lives. Almost four out of five people over age 65 have a chronic disease, and about 70% have two or more chronic conditions that need to be managed.

Furthermore, it is Canadian families that frequently shoulder 25% of the total cost of palliative care, costs associated with home-based services such as nursing and personal care services. Bluntly stated, Canadian society is not well prepared for end-of-life care. Since many more of us are going to be involved – as lead actors or in supporting roles – over the next generation, we can no longer avoid the subject. In fact, we need to fuel a national discussion around it.

Given the two hats I mentioned earlier, I have somewhat of a head start in thinking about it. I run an organization with close to 3,000 employees, and at any given time, some of them will likely be involved in caring for a dying spouse, father or mother, sister or brother, son or daughter, or dear friend. The experience will typically be all-consuming, exhausting and emotionally draining. Work will be the last thing on their minds, and if they think of the workplace at all, it will be either as a support or a source of additional stress. Organizations are nothing without their people, and as CEO, one of my priorities is to make sure GSK plays a supportive role to our most important resource. We need to be there for our employees at a time when they may feel helpless, isolated and overwhelmed, and when – honestly – work should be the last thing on their minds.

Then there is my work with the Canadian Hospice Palliative Care Association, and how I came to be involved with this particular cause. Shortly after I became CEO in 1994, I was examining our charitable commitments and it occurred to me that we could do better as a company, we

could try to make a real difference for a cause that needed real help and that was important to our country and to our employees. We took the challenge to our employees and they chose Hospice and Palliative Care. We proceeded to invest a substantial portion of our Foundation giving to the cause. We have been involved ever since. And I wanted to get involved personally.

My own experience with end-of-life care is far from unique, and virtually everyone here will have their own stories to tell. My most recent experience with death and dying only reinforced for me the real need there is for quality end of life care in Canada. My mother –in-law passed away this spring. She died at the age of 96, having never spent any time in a hospital until the last two weeks of her life. Unfortunately it was an acute care hospital because there was no palliative care facility available in her community. The experience for her and her family was not a good one. Without going into the detail she did not die with dignity because of the way she was treated and the staff's lack of compassion for a dying person. That was very painful for her family.

Despite the universality of these experiences, and the pressing need for better palliative and hospice care, there are some major cultural barriers standing in the way. Palliative care is all about providing quality of life to those suffering terminal illness. But that is not how most people see it. Instead, they associate it with giving up.

Attitudes towards death and dying emerge from one's cultural background, religion and upbringing. In Chinese society, for example, there is a belief that even talking about death is bad luck. Some African countries handle dying and bereavement very well because it is better integrated into day-to-day life, takes place at home, and is a shared experience by the community and among volunteer care-givers. On the other hand, some western nations such

as Canada and the US have ‘medicalized’ death, removing it from the stream of everyday life and thereby making it more mysterious and something to be feared. Cultural barriers loom large in a multicultural society like Canada, but they are far from insurmountable. Palliative care is not a surrender to death, and dying is not a taboo subject. And yes, I do believe that the workplace can be a highly effective forum for challenging cultural barriers around death and for creating a climate of open dialogue and support for those dealing with end-of-life issues. We can change the narrative for ourselves and for our loved ones, and end the story on a much better note.

Let me spend a few moments on the experience of dying today. First and foremost, it is a ‘family affair’. Former US First Lady Rosalynn Carter once said,

“There are only four kinds of people in this world: those who have been caregivers; those who currently are caregivers; those who will be caregivers and those who will need caregivers.”

Each death will affect, on average, the well-being of five other people – family and loved ones. That’s more than 1.25 million Canadians this year and more than 2 million Canadians in 2036. Decades ago, death came more quickly and most of us died at home. Today, life is being prolonged and life-threatening conditions managed. More Canadians are dying at an advanced age – more than 75% of deaths are among those aged 65 or older. Finally, more people now die in hospital – despite the fact that most would prefer to die at home.

How does Canada rank today against other countries in terms of the end-of-life experience?

The Economist Magazine and the Lien Foundation compared 30 OECD countries and 10 other selected countries last year in a report called “The Quality of Death: Ranking end-of-life care

across the world". The study looked at key indicators including the overall healthcare environment for end-of-life care; the availability, cost and quality of care; and the existence of a government-led national palliative care strategy. Canada tied with the US in ninth place overall.

This ranking, I think we can all agree, is less-than-stellar. And improving it will not be easy, but it is critical. That is because the need for end-of-life care is not simply a health issue. It is a complex social and economic issue that affects individuals, communities and the workplace.

At present, hospice palliative care in Canada is a range of services offered through acute care hospitals, long term care facilities, residential hospices and in the home. The level and type of care needed varies based on the needs of the patient and family, the patient's medical condition and rate of decline, and finally, the setting of care.

Despite the tremendous work of the Canadian Hospice Palliative Care Association and its provincial affiliates, and the generous support these organizations receive from government and the private sector, we still have a long way to go.

Fewer than 35% of Canadians have access to palliative care services due to issues of funding, access and late referrals. As I mentioned earlier, families frequently shoulder a quarter of the total cost of palliative care, which often includes home-based nursing and personal care services. Now add in the fact that about 70% of those past retirement age have two or more chronic conditions that need to be managed. As life expectancy continues to rise, so too will the need to manage these chronic conditions.

Yes, we all need to be concerned about our ability as a nation to provide high quality end-of-life care to more people. But let's not forget that families of patients also need help navigating a troubled system to ensure that their loved ones are getting the care they need.

They need help coping with grief and they need support that removes some of the stresses and worries that pile on at the worst time in their lives. This is where we – Corporate Canada– can play a role. And one of the most effective ways we can do our part is through the compassionate care benefit.

At GSK, we define the compassionate care benefit as a leave from work so that employees can provide care and support to an immediate family member in cases of critical or terminal illness or other extraordinary circumstances. The benefit provides for up to 13 weeks leave over a two year period. For employees with at least three years of service they receive 13 weeks pay at full salary.

GSK's compassionate care benefit, introduced back in 2002, was groundbreaking – so much so that it caught the attention of the Government of Canada. Two years later, the Canadian Government established its own program based on our lead. Today, Canadians who need a leave of absence from work to care for a gravely ill family member can receive up to six weeks of Employment Insurance benefits under the federal compassionate care program.

Allow me to quote from the government website: "The Government of Canada believes that, during such times, you should not have to choose between keeping your job and caring for your family." I could not have said it better, and all of us at GSK are very proud to have provided the foundation and catalyst for a program that is available to help every working Canadian cope with one of life's most difficult crises.

In order to give you a sense of the impact this benefit can have, let me tell you the story of the first GSK employee to use it. I have changed this employee's name in order to ensure privacy is protected – but let me assure you this person is very real.

John used the compassionate care benefit in May 2002 following his mother's diagnosis of terminal stomach cancer. Her illness progressed rapidly but the benefit allowed John to be with her for the final two months of her life. His mom was 67 at the time and his dad was 69. Due to the shock of the terminal diagnosis, it was hard for them to process all the information they were being given.

With the leave of absence, John was able to accompany his father to doctor appointments to ask questions and clarify his mother's pain medication regimen. Most importantly, John's presence allowed his mom to do some of the simple things in life – like visit the hair salon to get her hair done. Near the end of her life, he was carrying her up and down the stairs as she was too weak.

John describes this time with his mother as a "gift from the company". He contrasts his experience with that of his brother, whose workplace would not give him any unpaid time off, forcing him to use his vacation time. The lack of support left his brother feeling troubled and disconnected, and shortly after his mother's passing, he quit the organization. On the other hand, John has moved on within GSK, onto global roles outside of Canada.

John's story, and others like it, makes a powerful case for providing this benefit to employees. Both brothers faced the swiftly impending, untimely death of their mother from cancer – a family crisis that one has to live through to fully appreciate the impact. At a time when all of

their thoughts and energy were focused on the family, one brother received compassion, support and empowerment from his workplace. The other received essentially nothing. One brother's relationship with his employer was immeasurably strengthened; the other's was broken beyond repair.

Now I know that championing change can be difficult, and that all benefits, no matter how powerful their impact, come with business implications and costs. So let's spend a minute looking at these aspects of the compassionate care benefit.

You might be thinking, "My organization is too large and our benefits programs are too entrenched for a change like this." I want to tell you that my own company is about as large and complex as they come. GSK is a global enterprise with close to 100,000 employees in over 100 countries. The human resources and benefits policies of our Canadian operations are closely tied to global initiatives, budgets and priorities. In short, if we could get this done, so can you. You might also be thinking, "My organization cannot afford this type of benefit". Cost was one of the major factors we looked at when we introduced this benefit. Our conclusion was that, depending on how it is designed, it should not cost more than a sick leave program. Finally, you might be thinking, "My company is just too small for this kind of program. We don't have the people, the resources or the money to offer it."

The reality is that almost half of the Canadian workforce is employed by companies with less than 100 employees. Extending this benefit to them is a difficult problem, and I don't have a solution in hand. But I do know that we need to find one. The five million people who work in small businesses are just as entitled to compassion and support in their time of need as anyone else.

The federal government employment insurance plan has been accepted by all provinces and offers all employees six paid weeks of compassionate leave over an 8 week period. Nine provinces have also amended their labour codes to protect the caregivers jobs. Alberta being the one that hasn't amended its labour code.

This is a great start. Without wading into the thick of a complex issue, let me just say that any move by government to extend job protection beyond eight weeks would be very welcome. Another key step would be an ongoing publicity effort to ensure that every employee of a small business is aware of their rights and their employer's obligations with respect to compassionate leave.

Implementation logistics and costs are important issues to manage, but they are still only part of the picture, and I challenge us all to think beyond them. We need to think about the stability and peace of mind that a compassionate care benefit brings to the employee during a time of great stress and upheaval. We need to consider all the positive spin-offs for the organization. With the certainty and predictability of this program, it is easier to plan a smooth transition for customers, partners and other team members during the leave of absence.

The reduction in stress will have a positive impact on productivity for the employee when he or she returns, and for their team during their absence. The program fosters greater employee pride and engagement, and enhanced corporate reputation. Every time the compassionate care benefit is used, an employee ambassador for the organization is born. All these powerful organizational benefits must be factored in when considering such a program for your company.

And then there is a benefit that won't show up on any profit and loss statement. I can only describe this from a personal perspective. Since the inception of the compassionate care benefit

at GSK Canada, we have supported 137 employees like John through some of the most devastating periods of their lives. It's hard to express the emotion that comes with knowing you helped someone through their darkest days. Let's just say you can't put a price on it.

Business leadership is about engaging the hearts and minds of your employees to encourage loyalty, commitment and productivity. During a harrowing time in which the employee is typically distraught and emotionally vulnerable, their memory will be seared with the events. Give them the time and space to engage completely on the task at hand – which is caring for their loved ones – and they will never forget this compassionate act.

John has not forgotten. Since his mother's death, he has become an advocate of hospice care. While living in Romania, he became the head of a committee whose goal is to build Romania's first hospice facility. So far, he has helped raise 2.5 million euros to make that happen. That's a powerful legacy to emerge from a family tragedy and a company's response to that tragedy.

Modern medicine has made great strides in helping us live longer and healthier lives. A child born in Canada today can expect to live to be over 80 years old. People who are now 65 can expect to live another 18 to 21 years.

Medical advances have also helped create the so-called "sandwich generation" – the large cohort of middle-aged Canadians who are caring for both their children and their aging parents. Several Canadian corporations have policies in place to support employees with parental care responsibilities, and to my mind the compassionate leave benefit is a logical extension of that support.

Eventually, death comes knocking at everyone's door. With our aging population, an ever increasing number of Canadian households will be hearing that knock over the next few decades. And the families of those needing palliative care will be stretched to the limit – emotionally and physically.

The question is, what can Corporate Canada do to help ensure that financial and work-related worries are not layered on at the worst possible moment?

We need to be concerned about our ability as a nation to provide high quality end-of-life care to more people. A ninth place showing on a global “quality of death” survey is not a point of pride – it's a wake-up call.

Moving up the global rankings will not be easy. It will require a comprehensive, systems-based approach, accompanied by sweeping policy changes by government, the health care system, the business community and other institutions.

However, we can make a good start, and we can make it today. Through the compassionate care benefit, companies can play a leadership role in helping employees and their families in a very meaningful way.

Through our leadership, Canadian business can help break down some of the cultural barriers and taboos around dying that I spoke about earlier. We can support employees, drive engagement and productivity, and contribute to creating a sustainable healthcare system.

From a human perspective, lending a hand to those who need it the most is simply the right thing to do. And when companies do the right thing, they contribute to their own success and they deepen that reservoir of goodwill that allows all businesses to operate in society.

GSK supports policy development that positively impacts the social and economic health of Canadians, and we are proud to offer the compassionate care benefit to support the health and wellbeing of our employees.

But my goal here today is not to shed light on GSK's efforts to support our people and improve palliative care in Canada. It is to encourage you to think about how you can champion this type of program in your own workplace.

I hope that I have provided you with the beginning of a strong business case for a compassionate care benefit program in your business. But I know that when you get back to your desk, you'll need more than a speech to start the ball rolling.

If you need help building your case, get in touch with me. GSK would be pleased to share our experience and insights with you, your CEO, your HR department, or anyone else interested in the compassionate care benefit. Additionally, you have each been provided some background and resources related to care giving issues at end of life – I hope you find them valuable.

As business people, we have an important opportunity here to impact people's lives in a truly meaningful way.

I urge you all to seize it.

Thank you very much.