COURAGE

Workplace Support for Employees Coping with End-Stage Cancer
CONTENTS

3  Introduction

6  Sharing the news

12 Connecting patients with support

21 Transitioning out of the workplace

27 Building human resources policies for life-limiting cancer
In 2008, the Canadian Cancer Society reported that an estimated 166,400 new cases of cancer would be diagnosed in that year. These diagnoses will launch patients onto a challenging journey of treatment and care.

While medical advancements mean that cancer is more treatable than ever before, the disease is becoming ever more present in our lives. Soon, according to the 2008 Report Card on Cancer in Canada, mortality from cancer will surpass heart disease as the leading cause of death in Canada.

This impacts not only patients, but their caregivers, friends, families and colleagues, thus touching the lives of many Canadians in many ways. Health Canada estimates that between 75% and 90% of home care is provided by informal caregivers. These caregivers need information of all kinds to not only help the loved one they are caring for, but also to help them get through this difficult period, and overcome their grief if their loved one passes away.

**Cancer in the workplace**

Illness, death and loss are natural parts of life, and the workplace is not exempt from these realities. It’s impossible for employees to leave serious health issues at the doorstep when they come to work. In fact, at a time when most other aspects of the employee’s life seem to be under threat, the workplace can often feel reliable and reassuring. Work offers structure and routine, social support from colleagues and managers and much-needed medical and wellness services.

It is critical that at this time workplace support holds steady. Organizations can offer support in the form of a comprehensive benefit plan, disability and life insurance, emotional support through EAP (employee assistance program) and other services, access to patient navigation and...
drug compensation programs and other informational resources.

The cancer journey—understanding palliative care

Many people are familiar with the oncological aspects of cancer treatment. Though their benefits are undeniable, treatments like surgery, chemotherapy, radiation therapy, biological therapy and other protocols can be intense experiences in and of themselves. Patients often need multifaceted support services to cope with the myriad side effects of cancer treatment, be they physical, mental or spiritual. This kind of support falls under the umbrella of what is called palliative care.

We often think of palliative care as something that is offered to people at the very end of life; however, palliative care is an integral part of all stages of cancer treatment. “Palliative care begins at the date of diagnosis,” explains Dr. Martin Chasen, a medical oncologist and palliative care physician at McGill University, Royal Victoria Hospital. Palliative care focuses on preventing and treating physical issues, such as pain and suffering, which can occur at any time, as well as psychological and spiritual issues. It is also offered to caregivers both throughout their time caring for loved ones with cancer and afterwards.

For many patients, palliative care is crucial to their health and well-being. The cancer treatment protocol may cause side effects that are just as difficult to deal with as the disease itself. “The big problems facing people with cancer is what is called PDF—pain, depression and fatigue,” explains Chasen. “You need to address those issues in order to improve the quality of life.” Fortunately, there are medications and treatments available to help control pain and other symptoms, such as nausea, loss of appetite and fatigue.

Though palliative care is offered throughout treatment in tandem with oncological care, there may come a time when palliative care takes over completely. As Chasen says, “At the date of diagnosis, patients may need more oncology care, but as the disease projectory moves along, patients probably need more palliative care than oncology care.” At this point in the journey, palliative care takes on magnified importance. The focus shifts to fostering maximal comfort and respect for the individual. Quality of life—both for the patients and caregivers—becomes key.
A scenario to consider

The death of an employee due to cancer diagnosis seems like an unthinkable scenario. With the development of new pharmaceuticals and advancements in medical therapies, cancer is now highly treatable—an intense experience, to be sure, but one that many people will live through. In some cases, it becomes apparent that oncological treatment may no longer be effective. Patients may be forced to transition to a new course, one that is often difficult to conceive of, let alone accept—end of life.

Though you might assume that an employee diagnosed with life-limiting cancer would want to stop working as soon as possible, this is not always the case. For some people, quitting work is not financially feasible; others might make a personal choice to keep working for as long as they can in an effort to maintain what feels to them like a “normal” life.

It’s also important to consider that the timeline for a life-limiting cancer prognosis is often uncertain. While doctors can estimate how the disease will progress, there are many factors involved that will affect the course of the illness, and an employee can live with the disease for weeks, months or even years.

10 Leading Causes of Cancer Deaths in Canada

Projections for 2005

**MEN**

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**WOMEN**

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In many cases, employers may already know if an employee is undergoing treatment for cancer. They might have already had discussions around the time of the employee’s diagnosis, to map out a plan for supporting the employee through initial treatments. Often this can include adjusting work arrangements by reducing the employee’s hours or allowing for them to work remotely. The employee might have needed time off for appointments or even short- or long-term disability leave to recuperate from surgery, chemotherapy or other intensive treatments. Drug coverage could also be familiar terrain, as the employee is likely to have had to determine which drug costs could be claimed through the workplace plan and where alternative coverage might be required.

However, the same employee may not have had such candid discussions with co-workers up to this point. If the employee negotiated a flexible work arrangement, adjusted workloads or took time off, colleagues would likely be aware, but they may not know why.

In most cases, employees do share their experiences with co-workers. Linda Ydreos is Senior Director of Benefits at Spectra Energy Transmis-
A difficult decision

The choice to tell co-workers about a cancer diagnosis can be very difficult. Employees may struggle with who they should tell and how to do it. “Employees want to share,” says Dr. Alain Sotto, an occupational medical consultant with the Toronto Transit Commission, “however, they want to share with a measured release of information.”

Human resources can offer support in this area, helping the employee to develop a strategy for communicating this information to colleagues in a way that is comfortable to them. Take direction from employees; ensure that they clearly outline their preferences, so that the news is disseminated in a way that they desire.

When the news is a terminal cancer diagnosis, the scenario becomes even more delicate. Employees who choose to share the news will likely have to prepare themselves to answer questions
from colleagues and discuss their illness more than they may feel comfortable. As Ydreos notes, “The employee’s right to privacy of all health information must be respected. Not only as a leader but now also as a cancer survivor, I fully understand the importance of respecting employee privacy guidelines. A strong commitment to privacy would in effect allow the employee to have one less thing to worry about in their journey to recovery.”

Helpful tips
Discussing a life-threatening illness can be a very difficult task for even the most skilled communicators. Sometimes people facing serious personal challenges find it easier to open up to a person who is not as close to them, because they don’t feel the need to protect the individual or soften the news.

In some cases, employees may feel most comfortable talking to their organization’s health department, human resources representative or a workplace friend. For benefits information, it is ideal for an employee to have one point of contact within the organization, in order to minimize stress and anxiety. The contact should have the official capacity and authority to address issues and answer questions about employee benefits and policies.

The following are some tips on communicating with employees with life-limiting cancer or their caregiver:

• Listen to your employees and let them know they can discuss their concerns openly and honestly with you.
• Clearly explain your organization’s policies that apply to their situation. Employees will feel more comfortable knowing what they can expect from their workplace.
• Reassure employees that you will honour their wishes—from the way in which you communicate the news to what actions you will follow through with on their behalf and how they will be honoured when they are gone.
• Assure employees that you will respect their privacy.

**How to communicate**

One of the challenges of communication is that individuals take in and process information in their own way. We all have our preferred methods of learning—some people like to read books, magazines and web sites while others learn better by talking their problems through with another person. Still others need to visualize a problem, in which case videos can be helpful, or interact with something hands-on. Many of us prefer some combination of all four methods.

When faced with a difficult challenge, some individuals feel most comfortable and in control when they can learn everything about the problem. They want to know all they can in order to plan their strategy. Others may feel overwhelmed by too much information. For them, just the issue alone is enough to digest, without adding to it the daunting task of sorting through mounds of research and opinions. They still want to know all they can, but they need to access the same information in a more measured, easy-to-handle way.

It’s important to consider these innate personal differences when communicating with an employee who is either coping with life-limiting cancer or caring for a loved one who is. For these people, their health situation will feel overwhelming on its own, so the stresses of work, finances and other practicalities of end-of-life might be too much to handle all at once. Whether explaining their options for leave, benefits or EAP services, employers can take cues from these employees as to how they would like to receive information.

For some people, it can be helpful to take notes during the discussions, to which they can refer later to reinforce what was talked about. This also
might help them call to mind questions they had but forgot to ask during the meetings, because they were too preoccupied or overwhelmed. Pamphlets, books, web sites and videos are all helpful resources that patients can refer to repeatedly and when they feel ready and able to focus.

**Communication support for caregivers**

Many of the communications challenges and strategies also apply when the employee is the one caring for a loved one with terminal cancer. It will still be a sensitive issue, and the employee may have some of the same apprehensions about sharing the news with colleagues and then dealing with their questions or well-intentioned concerns.

The caregiver may also require time away from work to care for their loved one, which can cause additional stress. They might feel anxious or concerned that their job will be threatened by taking leave. Open communication with human resources can help ease these worries. Together you can develop a plan for adjusted workloads, flexible hours or time away, if needed. And once you open up the discussion, you can reassure the employee that their position will be there for them when they are ready to return. A gradual return-to-work plan can also be created in advance. At a time when so much is uncertain, and an employee is confronted with the unfathomable reality of losing a loved one, knowing that these supports—financial and emotional—exist can be a great relief.

**COMMUNICATION SUPPORT FOR CO-WORKERS**

It’s also important to provide guidance and support to the employee’s co-workers, so they understand their colleague’s wishes and have some parameters for how they should behave. The news that a co-worker has terminal cancer is very difficult to digest, and in many cases, people may not know how best to react or reach out—or even if they should. As well, every situation is unique, so they will not be able to guess what their co-worker needs and wants in terms of support from them.
Keeping in contact with a caregiver during time away from work can be very helpful. Caring for a loved one through to death may have changed the employee on a fundamental level. It’s understandable that the employee may feel some fear and anxiety about going back to work after such a life-changing experience. Again, the employee may wonder how to deal with questions from co-workers or what kinds of emotions will arise if conversations about the experience come up at work.

Periodic check-ins with a manager or close colleague can help ease these worries. They can discuss what the employee would prefer and that information can be communicated in advance to colleagues so they won’t feel uncertain about how to behave. Staying in touch will also help reassure employees that their job remains and they are welcome to return when they are ready.

**Communication support for managers**

Managers may need additional support as well. Discussing a terminal illness is a difficult conversation. Support and training are needed to help managers know how to conduct a discussion about these issues.

“Many people managers don’t know how to converse with a disabled employee,” explains Jamie Farrell, Manager of Benefit Programs at Rogers Communications. “It can be an uncomfortable conversation and it often is not something on which managers are trained.

“One important thing to remember is not to treat your disabled employee like a patient,” Farrell says, “but rather to speak to them as a person. Some employees may feel comfortable speaking about their condition, while others would prefer to speak about anything but. Making the employee feel connected and comfortable in the conversation are critical to maintaining an ongoing dialogue.”

Managers also face the challenge of communicating the news to the rest of the employee’s colleagues. “If employees share the news with their supervisor, which they usually will, that doesn’t mean managers have to send an employee communication on how to deal with it,” explains Dr. Sotto. “It has to be a one-on-one basis. We need to support the manager who’s going to be dealing with them on a regular basis.” Employers can leverage EAPs and other resources to provide guidance to managers in this area.
Individuals diagnosed with cancer are forced to confront many questions. They are entering a whole new realm of healthcare where they’ll have to learn about treatment options, costs and reimbursements, side effects, emotional fallout and recovery. They may question the cause of the disease, how they’ll cope with the treatments and how they’ll pay for it all.

When that diagnosis becomes terminal, these anxieties are compounded. They may think about who will look after their loved ones when they’re gone, how they will manage the pain that may accompany their disease as it progresses and how they will pay for the medication that may help them along the way.

More immediate thoughts might turn to their job and how long they will be able to live a “normal” life. They may also be concerned about revealing their diagnosis to their employer: will they lose their job immediately—and with it their benefits, disability coverage and insurance? Suddenly, everything feels under threat.

“Employees who are diagnosed with cancer face enormous challenges,”

“Employees who are no longer receiving chemotherapy can still get care and support—pain relief and symptom relief and emotional support—which are very important at the end of life stages. Patients don’t want to feel abandoned—it is their biggest fear.”

—Dr. Martin Chasen, Oncologist, Palliative Care Physician, McGill University, Royal Victoria Hospital

CONNECTING PATIENTS WITH SUPPORT
says Ydreos, drawing on her own experiences with cancer. “All the way from getting over the initial shock and maintaining a positive outlook, starting their treatment—every stage of which never seems to go fast enough—to dealing with the impact on family members, worrying about being absent from their job, to sometimes even having to deal with the perceived stigma of having being diagnosed with the disease. Personally, I found that setting up a network of support individuals made up of family, friends, co-workers and cancer survivors is essential in coping with these challenges.”

**Caregiver support**

Caregivers also need support. They can often be charged with securing coverage for drugs, figuring out who the patient needs to deal with in a complex healthcare system and how to get access to the supportive services their loved one needs. They may have many questions about what to expect as the illness progresses and how they should respond, according to their loved one’s wishes. Legal and financial issues are also practicalities that they cannot ignore. In addition, they will need support and guidance to maintain their own emotional and spiritual well-being as best they can during this time.

Once a patient transitions fully to palliative care, caregivers can be faced with a whole new, unfamiliar network of supportive services. Even though supportive services exist for those coping with terminal cancer, caregivers are not always aware of them. And, because they have no

**ROLE OF THE WORKPLACE**

During this tumultuous time in the employee’s life, workplace support is vital. “It’s critical to ensure that that employee knows that his benefits are preserved,” explains Dr. Sotto. “That really eases the pain from the financial perspective.” But the employee’s financial concerns are not the only needs that workplace support addresses. Services offered by the workplace—as well as the function of connecting employees with resources and outside support organizations—can help with all aspects of end-of-life cancer issues.
knowledge that these services exist, they don’t ask for them. In fact, caregivers can feel slightly lost and abandoned in this new reality. This can cause additional stress, anxiety and fatigue for them as they struggle to relearn the health and wellness landscape.

**Decision aids**

Individuals who have transitioned from oncological to palliative treatment may have very different visions of their future, however limited it may be. When faced with the possibility that life may end within a foreseeable timeframe, some people may want to extend their life as long as possible; others might choose instead to minimize the healthcare costs they will incur over the remainder of their lives. They may want to leave loved ones with as much financial support as possible or lessen the amount of debt that family will inherit. In each case, the path they choose will affect the kind of support they will need, from medical professionals, wellness services and the workplace.

The choice to accept or refuse an expensive medication that could prolong life or help ease pain and suffering as the disease progresses is an extremely difficult and personal one. As well, many medications have side effects that themselves might be challenging to deal with. In some cases, individuals may feel as though they’re faced with the choice between quantity and quality of life.

Employees often lack the help they need in making these vital decisions. “These are really difficult decisions to have to make,” says Jay Mayers, Senior Manager, Market Access, Private Insurance, at Amgen, “and without being given the appropriate tools or guidance, oftentimes patients are making

> Canadians always think the healthcare system is going to be there. It’s not until you have to deal with a life-threatening disease that you learn what the limits are.”

—Colleen Savage, President and CEO, The Cancer Advocacy Coalition of Canada
them in a bit of a vacuum.” Some individuals may feel conflicted also by the feelings and opinions of loved ones, who may not agree with or understand their preferences.

In the workplace, employers can provide decision aids—tools, such as videos or booklets, which help guide employees through the planning process. Decision aids provide individuals with information about the issue and explore the options open to them, as well as the possible outcomes, including harms and benefits that may result. They help people become active in their own decision-making, giving them the power to choose a course of action that they will ultimately feel comfortable and confident with, knowing that they have weighed all the possibilities and are aware of the potential results.

Reimbursement of drug and medical costs

Canadians generally pride themselves on having what they believe is an inclusive healthcare system that provides access to treatments for all citizens. Those who have never found themselves thrust into the cancer care system usually don’t realize that private payers, compassionate care programs and even patients themselves share the costs of these drugs and treatments. As Colleen Savage, President and CEO of The Cancer Advocacy Coalition of Canada, explains, “Canadians always think the healthcare system is going to be there. It’s not until you have to deal with a life-threatening disease that you learn what the limits are.” The reality is that an increasing number of drugs are only covered through private insurance and some drugs are not funded at all.

This can be especially true for newer drugs provided in hospital-based clinics and take-home (oral, hormonal or injectable) cancer drugs. A follow up to the 2006–2007 Report Card on Cancer, published by the Cancer Advocacy Coalition of Canada, found that coverage of many of these drugs is not nearly as accessible or universal as many people assume. The report also observed a new trend in individuals’ access to certain newer drugs for cancer—the development of private and public initiatives aimed at providing drugs on a pay-as-you-go basis.

The report describes different types of limitations that exist for the drugs studied.
• **Eligibility**—Drugs are publicly funded for patients who meet certain criteria; each case is reviewed individually.

• **Subgroups**—Drugs are publicly funded only for certain groups; for example, individuals who are over 65 years old.

• **Availability**—Drugs are publicly funded but are not available at all cancer centres and hospitals.

• **Lack of public coverage**—Drugs are not funded publicly at all. Instead patients or other parties (employer and/or pharmaceutical company compassionate use program) assume the costs.

Access to cancer drugs varies greatly among the provinces and is changing all the time. Currently, the western provinces—British Columbia, Alberta, Saskatchewan and Manitoba—enjoy the most comprehensive plans, while the Atlantic provinces call on private payers to pay a greater proportion of drug costs; Ontario and Quebec fall somewhere in between.

For patients, it can be difficult to negotiate the system and find access to the drugs they need. It’s hardly what they would prefer to focus on during a health crisis, and it can take its toll. “While Canadians enjoy the

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**PUBLIC PAY** for take home cancer drugs by province

*expressed per incident cancer case for 2002–2007*


16  COURAGE: Workplace Support for Employees Coping with End-Stage Cancer
benefits of a public system,” says Laura Blair, Private Healthcare Manager at Roche Canada, “the reality in healthcare today is that patients are not always getting access to the medicines their physicians want to prescribe. This is especially true with the newer generation of biologic drugs, where it can happen that neither the government or private insurer will cover the costs. At that point, patients already faced with the stress of cancer find themselves and their families shifting their focus away from recovery and become immersed in navigating the red tape of trying to broker some level of funding between these parties and even dipping into their own savings.”

From the patient’s perspective, it doesn’t matter who funds the cost of their cancer drugs—whether it’s government, insurers or compassionate programs—access is all they care about. What they don’t need is the stress of having to identify the appropriate payer or the worry of not finding coverage at all for a critical drug.

However, help does exist. The patient’s healthcare team can help determine if the drugs needed are covered under a public or private healthcare plan,

**PRIVATE PAY** for take home cancer drugs by province

*expressed per incident cancer case for 2002–2007*

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and many hospitals now have medical access coordinators on hand to work with the physician, patient and insurer to coordinate the paperwork required to file for reimbursement. Paulette Birmingham, drug access coordinator at Sudbury Regional Cancer Program, has first-hand experience assisting patients. “When we meet with the patient, we can tell they are worried about the drug coverage,” she says. “Our primary focus is to remove the financial burden. We want the patient to focus their energy on managing their disease and not worrying about drug costs.”

There are also several organizations and pharmaceutical companies that provide guidance and assistance to help patients find reimbursement for their cancer drugs. These programs can help patients figure out what drug reimbursement programs they qualify for and what documents they will need to submit. Many also offer financial assistance and direct patients to clinics that can provide these treatments. “Often these programs provide patients with their last hope of accessing treatment,” says Helen Siomos, Market Access Manager at Bristol-Myers Squibb Canada. Caregivers can also work with these patient-support programs, as the patients themselves are often too weak to speak to administrators for extended periods of time.

There’s also DrugCoverage.ca, a web site directed at patients, that explains all the different payers—provincial, federal and private—and provides information about plans—who is eligible and what drugs are covered. Most importantly, it gives information on special authorization. DrugCoverage.ca publishes the criteria for special authorization drugs, as well as all the forms, letters and other documents that patients and physicians will need to complete in order to file for reimbursement.

**Patient navigation and case management**

The cancer healthcare system can be overwhelming, especially for those individuals facing end of life. Throughout their cancer journey, patients may have to work with private payers, occupational physicians, cancer agencies, doctors and other medical or health professionals, each accompanied by its own set of procedures and paperwork. If it comes to a point where individuals need to transition fully to palliative care, this landscape may shift once more, and they’ll have to readjust to a new framework of care.
A comprehensive and coordinated end-of-life employee program includes tools that support the employee throughout the cancer journey, such as insurance, drug reimbursement, counselling, disability leave and other programs. The web of support can be widened even further with patient navigation or case management programs, which help demystify the system for patients and ensure they get the highest quality treatment possible.

Through these programs, case managers provide one-on-one support to patients and caregivers to help educate them about their cancer and its treatment, reinforce the importance of following through with their doctor’s care plan and assist with side effects of therapy. Through telephone support, counselling services and care coordination, case managers work with patients and caregivers to help avoid or delay hospitalizations and guide them through end-of-life decision-making, if that situation arises.

For employers, case management can result in cost savings. These programs encourage patients to take an active role in their health in a positive way. As patients become more knowledgeable about their disease and its management, they are better able to avoid or prevent complications and get the support they need early on. Case managers also evaluate and monitor the patient’s treatment and communicate regularly with the employer regarding claims.

**Employee and Family Assistance Programs**

The idea of a terminal cancer diagnosis seems almost impossible to accept. An individual faced with this prospect might have already travelled on a long road through various cancer treatments—surgery, chemotherapy, radiation therapy and other approaches—but that does not make the outcome any easier to process. Emotionally, cancer can take a huge toll on both patients and caregivers. Individuals are likely to experience feelings of anxiety, fear, anger, depression, sadness and despair at various stages.

In these situations, the support offered by Employee and Family Assistance Programs can make a huge difference in an individual’s well-being and mental health. “EAPs have evolved into a comprehensive source of support and resources that can greatly benefit an employee facing serious or terminal illness,” explains Jonathan Winston, Regional Director, Business Development, Eastern Canada, for Shepell-fgi.
Flexibile Work Arrangements and Disability Leave

Another key support that can be offered by the workplace is the ability for an employee—whether a patient or a caregiver—to take time away from work. This may include hours or a day for medical appointments, a week off for surgery or even months off as part of short- or long-term disability leave.

In addition to leave paid through their employer, employees may also be eligible for various types of leave through their provincial government. For example, in Ontario, those caring for a terminally ill family member may be able to take advantage of the province’s Family Medical Leave and could claim Compassionate Care Benefits. Other provinces offer similar programs.
While some employees may want to stay at work for as long as they can, at some point in the cancer journey, it is no longer practical. When cancer progresses beyond treatment’s reach, an individual’s mental, emotional and physical strength will inevitably begin to wane. If this happens when an employee is still actively working, it might also become difficult for their colleagues to cope with the realities of what the individual is experiencing. The scenario can take its toll on the entire workplace environment. And, at a certain point, it will make sense for the employee to begin to transition away from working life.

Some employees may find it difficult to arrive at this realization, as it signals a very real and final change in their life. Work can provide a sense of structure and normality, which is helpful at a time when life can feel out of control. There are options available, however, to make an employee’s transition out of the workplace less traumatic. Depending on your organization’s needs and the employee’s preferences and abilities, it may be possible to slowly reduce the workload, allow for the employee to work part-time or telecommute, or even transition the employee to a less-demanding and more flexible position within the organization.

“Maintaining contact with disabled employees, while they are away from the workplace helps in the success of any disability management program—but also can help the employee in their healing process as that connection to the workplace isn’t lost.”

—Jamie Farrell,
Manager, Benefit Programs, Rogers Communications
When planning the transition out of work, it is important to be sensitive to the employee’s situation. Taking immediate action by doing things such as removing an email account without notice would likely leave the employee feeling cut off and abandoned by their workplace. There has to be a period of adjustment where a plan is worked out between the employee and employer, so all parties know what to expect and what their roles are.

In some cases, the employee may work with outside vendors or clients, who will be affected by the transition. The change may need to be communicated to these other parties, keeping in mind that the privacy of the employee is paramount. Depending on the situation and the employee’s wishes, it might be appropriate for the employee to discuss the transition with clients or vendors personally. Or, managers may be called upon to explain the transition plan and reassure clients that they will be looked after.

**What employers can do**

One of the most helpful things an employer can do for an employee facing life-limiting cancer, or an employee caring for a loved one, is to give them access to tools and resources that will help guide them through their difficult journey. In many cases, there is so much going on in the lives of an employee in this situation that they may not even know what help they need or where to find it. Workplaces can fulfill a key role in this regard. “Employers can provide the individual employee with ready access to tools so they can ask the questions,” explains Dr. Sotto. “The reality is that patients are not going to look to empower themselves until they’re sick, so these tools can be very helpful to them.”

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**CAREGIVERS**

Caregivers may only need to leave work temporarily. In this instance, it’s still important to devise a transition plan for the employee’s leaving and return to work. Caregivers, too, may feel some anxiety about leaving work, and will worry about their job security and other issues. Communicating plans clearly and honestly helps reduce stress and anxiety.
Employers can provide toolkits, checklists and other resources to help their employees make sure everything is in order before they exit the workplace. For instance, employees will need to ensure that they have done the following:

- Identified beneficiaries on their insurance policies;
- Decided if they want an advance on a life insurance death claim; and
- Indicated if they will need private duty nursing, and verified that the costs can be reimbursed.

Employers can also provide a more detailed checklist of key issues or tasks that touch on other aspects of the employee’s life. Caregivers will often need to arrange their loved one’s affairs after they have passed and may find themselves saddled with an overwhelming number of responsibilities. With their minds and hearts fully occupied with caring, they may not fully realize all the practical things they will have to look after. Checklist items can include things such as the following:

- Locating a will, bank accounts and safety deposit box;
- Calculating and filing income tax;
- Notifying beneficiaries; and
- Transferring titles on properties and insurances.

Finally, an individual facing end-of-life issues will have to consider some rather difficult questions, such as where they would prefer to die, who they want around them at that time, how they’d like to be cared for and what should be done after their death. As Dr. Sotto explains, “To be comprehensive, you need an employee toolkit, a checklist that will answer questions such as, ‘Do I have a living will or medical directive? What are my instructions to health-care providers? Do I want aggressive resuscitation?’”

These are harsh topics to think about and discuss, but checklists that prompt these questions can be very beneficial. By considering these issues and telling loved ones and caregivers what they want, individuals can make sure that they are cared for in the best possible way. “It doesn’t have to be all-inclusive,” says Sotto, “but if you know how to ask the right questions, then you’re well on your journey.” Consider where the patient is in their journey to determine if it is the right time to ask these questions, so they can benefit from the discussion.

**Bereavement**

Even after a long battle with cancer, it can be a shock when an employee
passes away. Family, caregivers, friends and colleagues of the individual will all struggle in their own unique ways with grief and loss. Employers may still have a role to play as well, both in wrapping up the financial and logistical matters of the deceased employee, and in managing and supporting the health and well-being of the workplace in the face of such overwhelming grief.

When the news of an employee death is first received, it is appropriate to contact the family to offer condolences as soon as possible. Ideally, the employee will have designated a main contact person for the employer to deal with after their death to resolve any remaining financial and benefit matters. When dealing with this person, it’s important to remember what they are going through. It might be necessary to explain the process and answer many questions. Offering supportive tools and resources, such as pamphlets or web sites, can be helpful. That way, the contact person can review the material again if needed. For some matters—for example, requesting the return of company property, such as a laptop computer or cell phone—it’s best to be sensitive to the situation and wait until a reasonable amount of time has passed.

It is preferable to have a strategy in place for communicating the news to colleagues before the situation arises. For example, one plan could be to tell key co-workers one-on-one. These would be the colleagues closest to the employee or ones who will be most affected by the death. Then, a note could be sent to the remaining employees. If this was discussed prior to the employee’s departure, then the plan should follow their wishes accordingly.
As the news is disseminated throughout the workplace, employees will experience a range of emotions and reactions. At first, they may feel shocked, even if they knew the employee was seriously ill and progressing towards death. There is no normal way to mourn the loss of someone we care about. People will feel many emotions and express them in different ways. Don’t assume that because someone is not openly crying or expressing themselves that they are not deeply affected. They may need as much support as someone who is more vocal about their grief. For some people, their emotional reaction will translate into physical symptoms. They may lose their appetite, feel weak or experience a tightness in their chest or shortness of breath.

Colleagues and family members may need emotional support and counselling to deal with these emotions. Group sessions and individual support, offered through EAPs can be helpful. Family members may also be eligible to benefit from EAPs, and may not be aware that they still have

“The reality is that patients are not going to look to empower themselves until they’re sick, so these tools can be very helpful to them.”

—Dr. Alain Sotto, Occupational Medical Consultant, Toronto Transit Commission
access to this through their loved one’s benefits.

**Paying respects**

For those left behind, honouring their friend and colleague can be an important part of the healing process and the path forward through bereavement. Those most touched by the passing of their colleague may need time off to attend the funeral. Caregivers might require extended periods of time away to arrange their loved one’s affairs and properly grieve.

Employers might want to send a representative from the organization to pay respects at the funeral, donate to a cancer charity or send flowers to the family. In some cases, it might be appropriate to honour the employee in some way in the workplace. Managers can consult with the work team to gather feedback on what they feel is the best approach. Employees need to be the ones indicating the need and desire. Honouring a colleague can help alleviate feelings of sadness and loss, but only if it is what the grieving parties want. It should be clear to employees that it’s their choice if they want to contribute to a charity or participate in a memoriam.

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**THE LASTING EFFECTS OF GRIEF**

When an employee passes away, the workplace can be turned upside down for a time by the change, loss and grief. Even once routine has seemingly returned to normal, things will never quite be the same. Colleagues of the employee may deeply feel the loss for quite some time afterwards. This can affect their productivity, or result in increased absenteeism or even presenteeism, where an employee is physically at work but is unable to properly focus and be fully productive. A good approach to dealing with these issues is to be compassionate. Employers can offer support through EAPs and other resources that will help colleagues cope with the loss and move forward.
When an employee reveals that their cancer might be life-limiting, an employer may react in a number of ways. Usually, these reactions are motivated by empathy and the desire to give the employee the support they need in whatever way possible, whether they’re a patient or a caregiver. Even though these reactions are well intentioned, they can lead to problems if no policies exist to guide and support them.

When decisions are made in a reactionary way with no base parameters for how to proceed, these reactions can result in inconsistencies in what we give our employees and how we deal with them. If one employee is given extended time off to care for a loved one while another employee receives a different reaction, it can seem unfair. Employees, as a result, won’t know what to expect from their employer or what would be expected of them in such a situation. They can lose confidence in their employer and feel as though they would not be able to count on their workplace in tough times.

“When defining HR policies and how they extend into benefit programs, employers of all sizes need to be given an outline of best practices to support the patient or caregiver. We need to think from the foundation up about all the things that may be affecting this employee—whether they have cancer or they’re the caregiver.”

—Jay Mayers, Senior Manager, Market Access, Private Insurance, Amgen
an employer has to consider its brand and what it is trying to accomplish by offering these programs,” explains Farrell. “In taking a proactive approach in the design and development of HR/benefit programs, it establishes clear protocols for how the plan will support employees in a number of situations. Not doing this could cause the employer to be reactionary in its approach to more extreme situations. As well, it could create confusion for employees and possibly a perception of indifference or, worse, inequity.”

Each scenario is inevitably going to be unique—employees will suffer from different forms of cancer or their cancer will progress differently, they will cope with the news in their own way, they will have different supports already in place and they’ll make their own choices about the future of their work life and healthcare. However, a set of strong human resources policies can guide the roles, responsibilities and responses of the employer in these situations and help to ensure the employee receives appropriate support. “It’s important to be forthright with what the plan can sustain and to design the plan accordingly, so it doesn’t set artificial expectations,” Farrell says. “Defining the plan, and any underlying limits, in advance will lessen any confusion and set a tone that is applied consistently in all situations for all employees.”

Having policies in place can also be comforting to managers and employees alike. Defining everyone’s roles upfront can be immensely helpful, notes Farrell. “That way there are not as many surprises and you’re taking a more consistent approach and the level of understanding among your employees can be greater.”

Also, communicating at this time can be very awkward and difficult. All parties can benefit from direction and support. Employees will also feel comfort knowing that the employer has thought of their needs in advance and cares about them.
From the ground up
When defining human resources policies for dealing with employees with end-of-life cancer, employers can start by identifying their corporate objectives and strategies. Then, ensure the policies align with them. The following are areas to consider when creating a plan:

1. Values of the organization
Reflect on the values that are set within your organization. Consider what role you want to have in caring for your employees. This should then cascade down to all levels.

2. Demographics of the organization
People tend to remain in the workforce much longer now. In organizations where the workforce is more mature, the chance of illness among employees will be greater. The human resources policies created in such an organization should take those factors into account to determine how it can accommodate them. Employers may also need to consider the wisdom and experience that these mature workers bring to the table. What would happen if this was lost? It may be necessary to implement a contingency plan—a strategy for the organization that would be put into effect if certain key employees were to pass away or no longer be able to work.

3. Goals of the program
Decide what function you want the program to have in advance. For example, will your plan focus on compensation, or will you create a plan that includes catastrophic insurance?

4. Communication policies
Create some guidelines about how information should be disseminated through the organization. Identify key contacts for the employees to come to with questions and provide support and training for these contacts so they feel equipped to deal with these delicate scenarios.

5. Leave and transition policies
Develop some parameters for granting time off for serious illness, whether it’s for patients or their caregivers. Decide when exceptions can be made and who should make the call in those situations. Create a strategy for transitioning employees out of and back into the workforce. Consider what you can offer in terms of flexible work arrangements.

6. Reimbursement policies
Consider what kind of drug coverage will be offered for catastrophic illnesses and what procedure you will follow in situations where a critical drug is not covered on the drug formulary. In this
INFORMING YOUR EMPLOYEES

The reality is that most employees don’t take the time to learn what their coverage is for a life-threatening illness until they are forced to deal with the situation. This is understandable, but there are some steps employers can take to help educate their employees.

To help employees understand their benefits, employers can conduct informational sessions, such as lunch and learns. They can also provide written materials and make information available on their internal employee web site. Examples of potential real-life scenarios can help employees understand exactly what the policies mean in practical terms. “One of the ways that employers help employees is in how they design the benefit plan and how they let employees know when they change that benefit plan,” explains Savage. Employees should understand that they are also accountable for understanding their own coverage.

case, employers can make an exception and decide to fund the treatment. Or, they can choose to refer the employee to other tools.

7. Supportive tools
Identify what tools, checklists and other supports you can offer to employees in situations of catastrophic illness.

Moving forward
While it’s vital to have policies, it should be with the understanding that they can be flexible when it is warranted. Policies are best viewed as guidelines, not hard and fast rules. There may be instances when it’s okay to make adjustments and should be clear who will make these decisions.

These policies, like all guidelines, should be reviewed periodically to ensure they still make sense and work for all parties. Any time the plan is revised, these changes should be clearly communicated to the employees.
If you have an EAP, don’t hesitate to direct employees to it for help. And encourage both patients and caregivers to write down all the information they receive. If they are in an emotional state, they may forget crucial points later on.
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**Employee Assistance Programs**
Shepell·fgi serves approximately 7,000 organizations, representing eight million employees and their family members. Through best practice triage and assessment, followed by care from an extensive network of counsellors, case managers and professional service providers, individuals receive the help they need to remain present and focused at work. We also support people leaders in ways unique to their role.

**Health Management**
Since not every condition can be anticipated and prevented, Shepell·fgi takes an innovative approach to health management by integrating programs and services that provide seamless support along the entire continuum of care from pre- and early absence through intervention and recovery, including successful return to work.

**Organizational Solutions and Training**
Shepell·fgi’s experts work closely with organizations to help them understand their unique workplace challenges, the causes of those issues and the solutions that will generate positive change and maintain high-functioning workgroups even during crises or times of significant change.

We also have a Research Group dedicated to educating business leaders on the impact that mental, social and physical health issues have on individuals and their workplaces. Through a variety of research reports, we share a wealth of information and analysis, contributing to Shepell·fgi’s position as a thought leader in employee health, wellness and productivity.
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