A Caring Voice

Stories of Caregiver Journeys in End-of-Life Care

Introduction

From the very first moment we come into this world our focus is on living well. But we cannot overlook the importance of dying well: at peace, unafraid, free of pain, in a location of our choosing, surrounded by loved ones, friends, pets, and even our favourite books, objects or music.

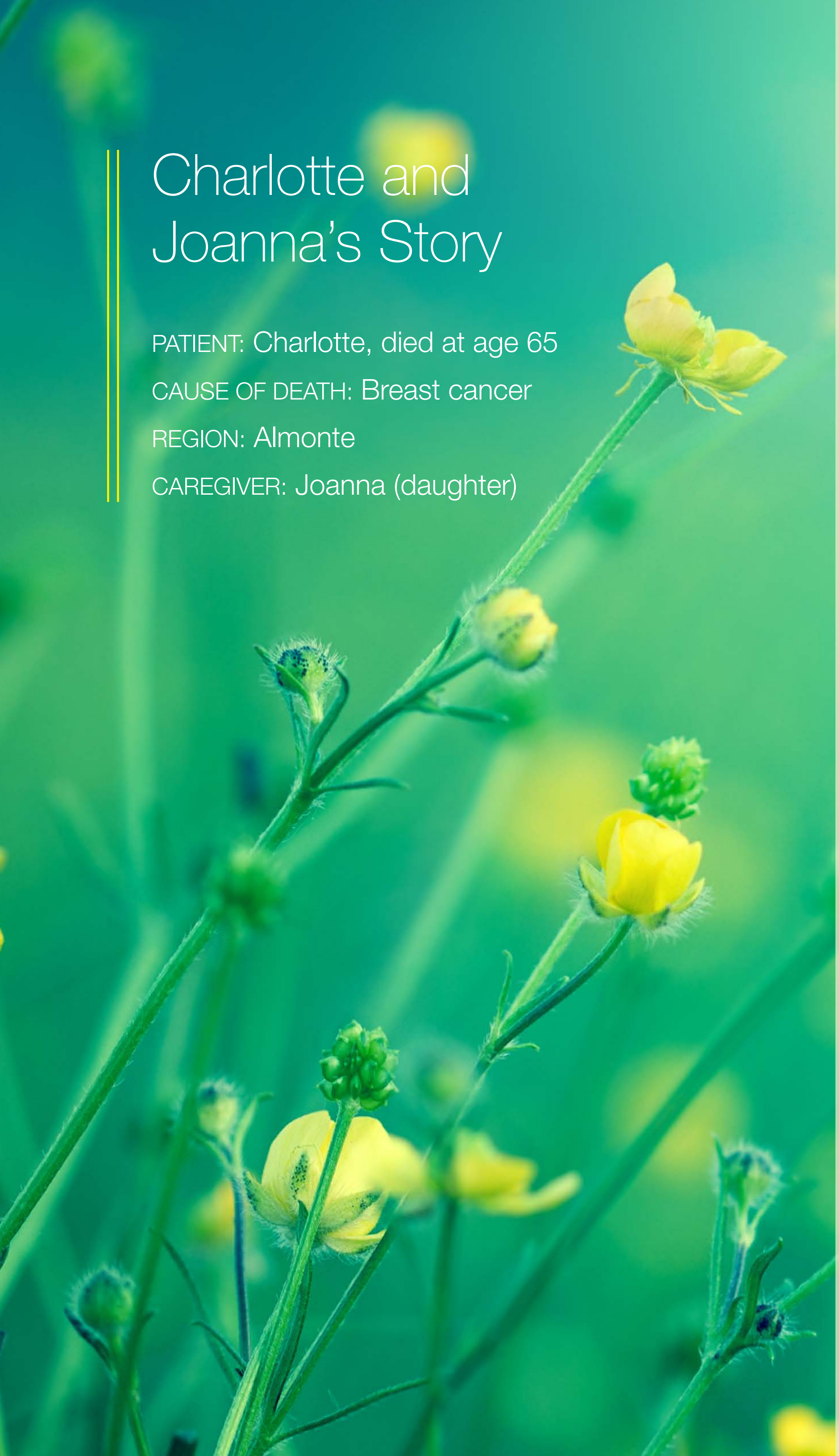
To have a 'good death' is not unrealistic. Medical, emotional and spiritual support systems, dedicated to improving the quality of life, and death, for patients and their caregivers are available in communities across Ontario. And yet much seems to stand in the way of end-of-life patients receiving the kind of care they need — as soon as they need it, ensuring they leave this world peacefully and with dignity.

As part of a recent Ontario-based research study into community-based palliative care, led by Dr. Hsien Seow, a number of caregivers (spouses or children of patients) were interviewed, in an effort to better understand how the current system is meeting the needs of both the dying and those caring for them. To learn what's working and where there's room for improvement.

The results can be found here. A rich collection of personal stories describing experiences with both the health care and additional end-of-life support received, by both patients and the family members who cared for them. In every story there is a connection to their local Community Care Access Centre (CCAC), the organization responsible for coordinating homecare services. All families navigated the same Ontario health care system, yet each experience is unique.

Heartfelt thanks go to all those who shared their stories. Although we have only included a small sample of those we spoke to, they've helped shed light on ways to improve end-of-life care.

Caring for our dying loved ones is not an easy task. But together, as a community, we can ensure that their death mirrors the way they lived. It is said "Just as dying is part of the life of an individual, and part of the life and history of a family, caring for those among us who are dying is part of the ongoing life of the community." (Dr. Ira Byock M.D.)



Charlotte and Joanna's Story

PATIENT: Charlotte, died at age 65

CAUSE OF DEATH: Breast cancer

REGION: Almonte

CAREGIVER: Joanna (daughter)

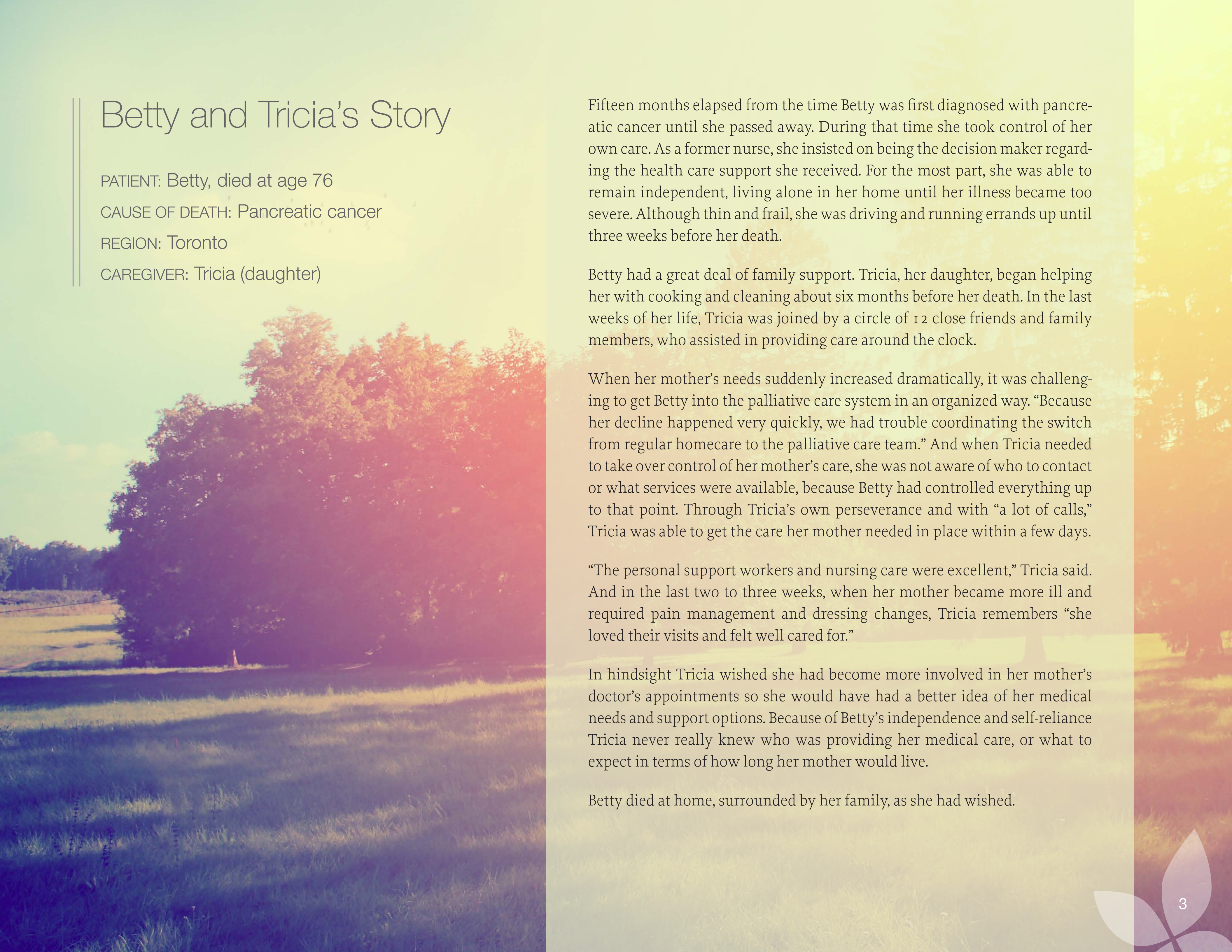
Charlotte found a lump in her breast in April of 2011. After a series of frustrating delays her mastectomy biopsy revealed an aggressive form of cancer.

Following difficult treatments of chemotherapy and radiation Charlotte continued to have distressing symptoms, culminating in congestive heart failure by June of the same year. In late June Charlotte and her daughter, Joanna, were told she had Stage 4 lung cancer and she was given mere months to live.

Her condition deteriorated rapidly and Joanna was told "CCAC nurses would come when they can." Joanna was left to care for Charlotte essentially on her own. Nurses visited only once a week, leaving Joanna confused and stressed because she felt ill-equipped to administer her mother's multiple medications, or manage their side effects. Attempts to have Charlotte admitted to hospice were met with delays.

After a particularly difficult night, Charlotte became terribly ill and the nurse called 911. She was admitted to Perth Hospital; and, later, was transferred to Almonte to be closer to Joanna and her family. Properly medicated, she passed away, peacefully, about two weeks later, in hospital — where staff had allowed Joanna to stay with her mother for her last days. She remembers, "the hospital staff were excellent … never got mad at my questions."

Caring for her mother Joanna felt completely unsupported. "I wanted to be a daughter, not a nurse," she recalled. Dealing with her own children, her father who suffered from dementia and her mother's complex and confusing medical needs was a "living hell." And to this day, she believes if she'd had the proper support she would have been able to keep her mother at home, and out of hospital.



Betty and Tricia's Story

PATIENT: Betty, died at age 76

CAUSE OF DEATH: Pancreatic cancer

REGION: Toronto

CAREGIVER: Tricia (daughter)

Fifteen months elapsed from the time Betty was first diagnosed with pancreatic cancer until she passed away. During that time she took control of her own care. As a former nurse, she insisted on being the decision maker regarding the health care support she received. For the most part, she was able to remain independent, living alone in her home until her illness became too severe. Although thin and frail, she was driving and running errands up until three weeks before her death.

Betty had a great deal of family support. Tricia, her daughter, began helping her with cooking and cleaning about six months before her death. In the last weeks of her life, Tricia was joined by a circle of 12 close friends and family members, who assisted in providing care around the clock.

When her mother's needs suddenly increased dramatically, it was challenging to get Betty into the palliative care system in an organized way. "Because her decline happened very quickly, we had trouble coordinating the switch from regular homecare to the palliative care team." And when Tricia needed to take over control of her mother's care, she was not aware of who to contact or what services were available, because Betty had controlled everything up to that point. Through Tricia's own perseverance and with "a lot of calls," Tricia was able to get the care her mother needed in place within a few days.

"The personal support workers and nursing care were excellent," Tricia said. And in the last two to three weeks, when her mother became more ill and required pain management and dressing changes, Tricia remembers "she loved their visits and felt well cared for."

In hindsight Tricia wished she had become more involved in her mother's doctor's appointments so she would have had a better idea of her medical needs and support options. Because of Betty's independence and self-reliance Tricia never really knew who was providing her medical care, or what to expect in terms of how long her mother would live.

Betty died at home, surrounded by her family, as she had wished.

Phil and Bonnie's Story

PATIENT: Phil, died at age 64

CAUSE OF DEATH: Brain cancer

REGION: Toronto

CAREGIVER: Bonnie (wife)

Phil was diagnosed with a malignant brain tumor in September of 2012, after experiencing difficulty writing and following directions.

After being his sole caregiver for 6 months Bonnie, his wife, was looking forward to visiting her daughter in Scotland for a much needed break. The plan was to have Phil admitted into hospice care. When that was unavailable, he was admitted to Toronto Grace Hospital Palliative Care Unit, where he'd be cared for until Bonnie returned home.

The day after Phil was admitted Bonnie returned to find him lying naked on his bed, with a room full of dirty dishes. When a 2-hour nose bleed went untreated by the hospital staff, Bonnie, who felt her husband was being neglected and her concerns were being dismissed, realized this was not the place for Phil.

Worried about leaving him in this condition, Bonnie decided to bring Phil home and cancelled her trip to see her daughter. As his condition worsened and Bonnie needed more help, they had more visits from personal support workers, who Bonnie said were "marvelous."

After a stay at Princess Margaret Hospital, where Bonnie described staff as "amazing" Phil was admitted to Kensington Hospice where he spent the last two weeks of his life, and eventually passed as he had wanted. Bonnie remembers the time at Kensington as "wonderful," praising the visiting palliative care physician for keeping Phil comfortable as he passed.

Bonnie said of the Kensington staff, "they let me bring our dog in to visit Phil and the hospice staff were always available for hugs and support."

John and Charlotte's Story

PATIENT: John, died at age 71

CAUSE OF DEATH: Chronic Obstructive Pulmonary Disease

REGION: Grey County

CAREGIVER: Charlotte (wife)

John was cared for, at home, by his wife Charlotte because that's what she promised him. A retired nurse, her experience was part of the reason she could be an advocate for his care. When John was transferred to a palliative care team in April 2012 Charlotte took issue with the inconsistencies that followed:

She was frustrated by the fact that the nurses who visited were too unfamiliar with both his status and his needs, as they were outlined in his medical records. For example, the nurses believed John was on intravenous drugs, which was not the case for some time.

These issues caused added stress, for both John and Charlotte, who remembers how difficult it was for her husband to "deal with nurses he didn't know, who weren't up to date on his current status."

In May, Charlotte went to CCAC asking for more provider consistency in her husband's care. She specifically requested two nurses in particular, because she felt others had "talked down to me and the rest of my family. They made us feel stupid and I didn't feel they respected my husband [John]." Requests for a specific nurse, as well as overnight care were denied by CCAC due to staffing and funding restrictions.

In the end, Charlotte persisted and John received care from a wonderful homecare nurse who gave the consistency and care they were so desperate to receive. Both Charlotte and John got the support and compassion they needed from the palliative care doctor and nurse practitioner who cared for John at the end.

Charlotte stressed that caregivers need to be better supported and that doctors and nurses need to be appropriately educated in palliative care. As a nurse, Charlotte was well equipped to care for John but she emphasizes "People need to realize that the actual end comes so quickly."

Rick and Pat's Story

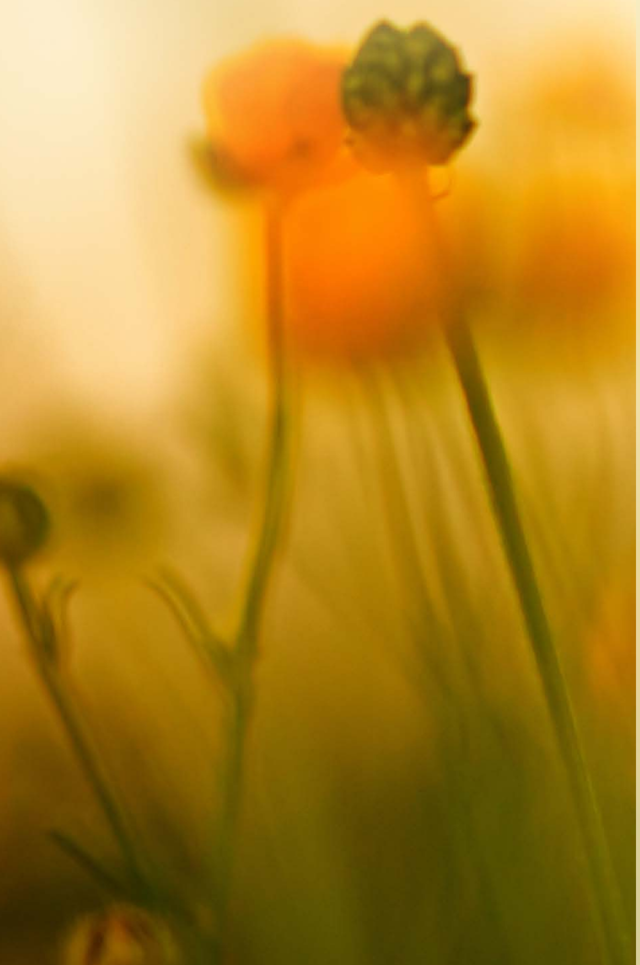
PATIENT: Rick, died at age 61

CAUSE OF DEATH:

Esophageal cancer

REGION: Smiths Falls

CAREGIVER: Pat (wife)



Rick was cared for by his wife, Pat, a health care worker. He died at home. Pat described the homecare support they received as "a patchwork quilt of caregivers, with large gaps in communication."

The lack of communication, training, materials and access to care plagued Pat as she cared for her husband during his illness. Supplies would arrive at their home without instructions; and, in some instances, when they didn't arrive or when there wasn't enough, she would have to pick them up herself.

Pat felt she didn't have clear information on who to call when she could no longer care for Rick without help. Instead of giving the contact information to her, it was given to Rick while he was still relatively well — but he couldn't pass it on when he became too ill. Another issue concerned the lack of nurses' availability, particularly in the last days of Rick's life, when they were needed the most.

It was felt that the nurses were not equally prepared or trained. Some seemed more confident in their skills than others. Once, for example, a procedure resulted in a PICC line (peripherally inserted central catheter) infection that significantly delayed chemotherapy treatment and saw Rick hospitalized.

In the last few days of Rick's life when Pat requested more help dealing with the ever-changing medications needed to control her husband's pain she was told nothing could be done for a week. Unfortunately, Rick's condition deteriorated so quickly, by the time the extra help was available it was too late.

During the final hours of Rick's life he was in agony, unable to breathe. When Pat requested help she was told "there is no money in the budget for another visit," leaving them both unsupported. On that day, Pat wanted to give him additional pain medication but was told she had to wait for the nurse. "I knew he was dying," she said and added, "I was desperate for help but didn't know where else to go or what to do." By the time the nurse arrived, Rick had died.

When Pat recalls those last hours of Rick's life, she says "patients should not die in such distress and pain, nor should families face such barriers when their loved one is dying at home. This was a catastrophic system failure." Even following his death the system broke down for Pat. After requesting equipment be removed from her home as soon as possible, it remained there until she followed up several days later.

Pat blames organizational issues and a systemic communication breakdown for the difficulties she faced and the stress it caused. And despite being a health care worker herself — with access to resources and system knowledge the average caregiver doesn't have — she still felt she couldn't adequately navigate the system to both manage the significant burden of caring for her husband and ensuring a 'good death' experience for him.

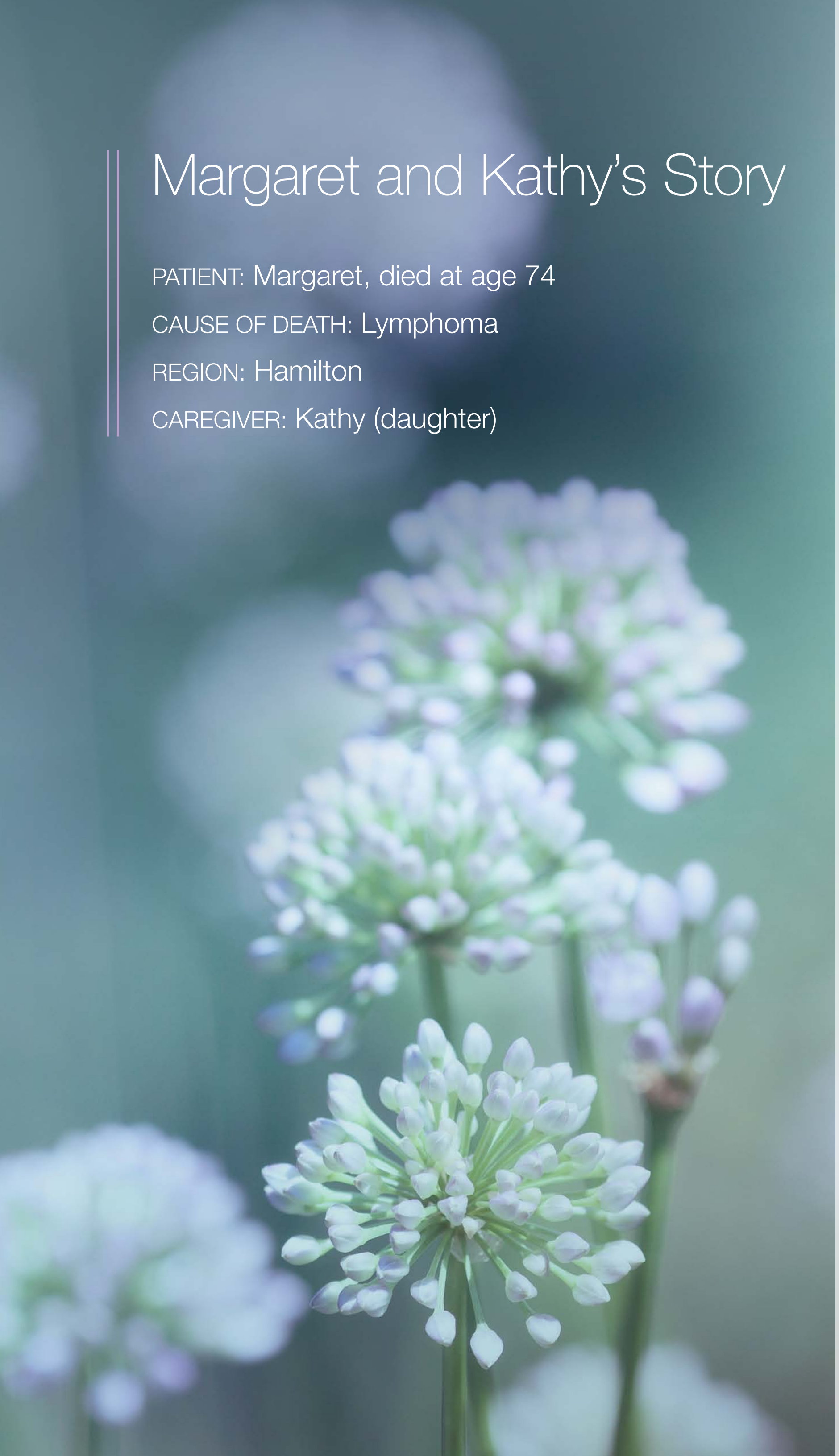
Margaret and Kathy's Story

PATIENT: Margaret, died at age 74

CAUSE OF DEATH: Lymphoma

REGION: Hamilton

CAREGIVER: Kathy (daughter)



It took about three months from the time Margaret and Kathy were told Margaret, who had lymphoma, was terminal to when she died. Despite the fact that palliative care was not available where they lived, Margaret's family doctor is an advocate for local resources and he made sure they had the support they needed.

Personal support workers and nurses came every day and were excellent. In addition to taking good care of Margaret, they communicated well with her family, answered their questions and addressed their concerns.

Margaret asked to be placed in Bob Kemp, their local hospice, when it got to be too much to care for her at home. With the understanding they were placed on a waiting list they left the hospital and waited. After some time passed with no news Kathy inquired with CCAC. They followed up and it was determined the hospice had no record of Margaret wanting to be there; and, therefore, she was never placed on a waiting list.

Not knowing who to call at this point, Kathy was subjected to a round of "phone tag" with the CCAC and the hospice. The time spent on the phone, trying to get answers, was unnecessarily time consuming and frustrating — especially as it was going on during her mother's last days.

Margaret never was admitted to Bob Kemp Hospice. Her final days were spent at home. She was scared and made irrational decisions. For example, despite being in a great deal of pain she refused pain medication — even though the homecare nurses were wonderful and did their best to ease her fears.

Kathy stressed that "a central point of contact at CCAC — someone who knows the big picture — is important so you can ask all your questions and get the correct answers promptly." Clearly better communication between all parties could have made Margaret's and Kathy's journey easier.

Tony and Jane's Story

PATIENT: Tony, died at age 69

CAUSE OF DEATH: Metastatic cancer

REGION: Toronto

CAREGIVER: Jane (common law partner)

Tony's treatments primarily took place at Princess Margaret Hospital in Toronto. Jane, his long time partner and common law spouse, went with him to every appointment. She was treated as a spouse, felt involved and was kept well-informed by all of his Princess Margaret Hospital health care providers.

On one particularly traumatic night when Tony was in severe pain, he was taken, by ambulance, to the nearest hospital. Because his Princess Margaret Hospital records were not available to the emergency room doctors, Tony and Jane had to recount his entire medical history — which delayed treatment at a time he desperately needed pain relief medications. To make matters worse, they were also told their palliative care physician, who had previously treated him, did not have privileges to see them while Tony was in this particular hospital.

Back at home, Jane "felt invisible" to the personal support workers caring for Tony. At no point did the nurses ask for the name of Tony's primary caregiver and power of attorney; and, as a result, Jane was excluded from any decision-making. Instead, the nurses turned to Tony's children, who were only available near the end of his life.

Despite being heavily involved in his treatment and care at Princess Margaret Hospital, Jane felt "helpless and uncertain as to what was happening in the last few weeks of Tony's life." She needed more emotional support, both during Tony's end-of-life care and after he passed away. "The name of the health care power of attorney should be one of the first questions asked when a patient arrives at hospital or for any medical appointment."

Tony died at home with Jane and his family by his side.

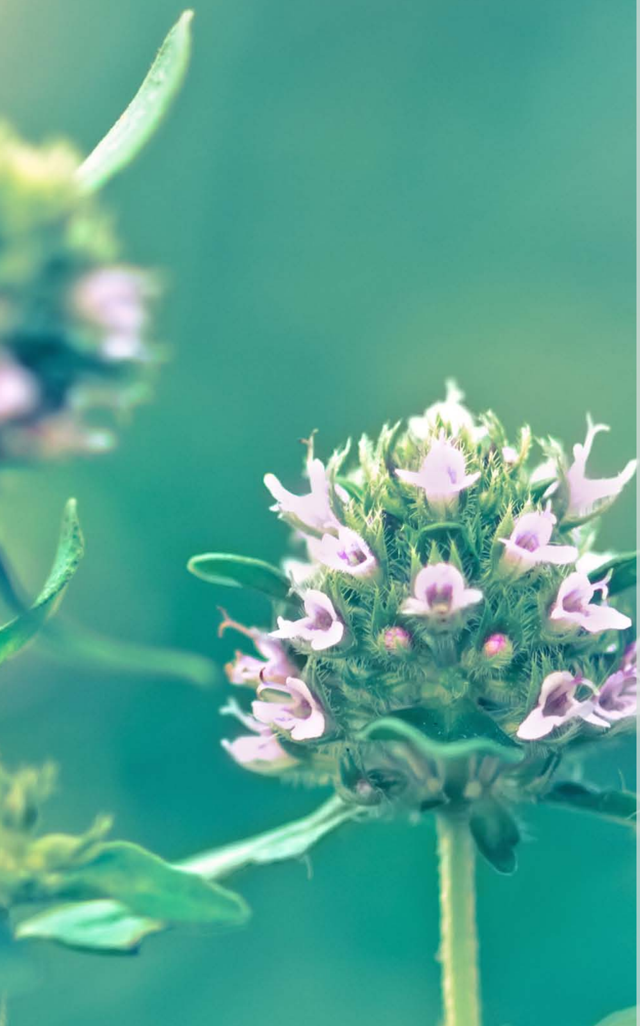
Kim and Joe's Story

PATIENT: Kim, died at age 32

CAUSE OF DEATH: Breast cancer

REGION: Brantford

CAREGIVER: Joe (husband)



It was in 2009, just two weeks after she met Joe, that Kim was diagnosed with breast cancer. One week later, she'd met with an oncologist and began chemotherapy.

Two years passed and, in that time, Kim and Joe were married, bought a house and began renovations. In early 2011, in the midst of ongoing renovations, Kim was having difficulty managing the effects of her treatment and required some home nursing care.

In that same year Joe felt ill and, after a series of tests, he was diagnosed with lymphoma. On the same day he received his news they were also told Kim was terminally ill; and they were advised to begin preparing for the end of her life.

"Afraid if she went into the hospital she'd never come out," Kim wanted to remain at home. The fact that Joe was, at the same time, battling cancer and undergoing chemotherapy made this an exceptionally "difficult time" for the pair. A homecare team from Stedman Hospice, in Brantford where they lived, were able to come to their home and help Joe care for Kim.

At the beginning they saw just one doctor and a nurse. But their support team quickly grew and Joe smiles as he remembers, "Whoa, we've got six people coming to see us now." Both Kim and Joe felt so well supported.

The care team knew them, and understood what they needed. They knew that to properly support Kim, they also needed to support Joe so he could care for his wife the way he wanted. They even taught him how to give Kim her injections, when the time came, so he could do it comfortably and confidently.

They also prepared Joe for what lay ahead, explaining what to expect as she got closer to the end of her life. "They went through all of it with me, so I was ready and unafraid."

When Kim did pass away in late 2011 the team was there for Joe, supporting him through the grieving process as well. His wish is for "everyone caring for a loved one to have the support of an end-of-life palliative care team."

In gratitude for all they did for him and Kim, to this day Joe supports Stedman Hospice through volunteering and by participating in their fundraising initiatives.

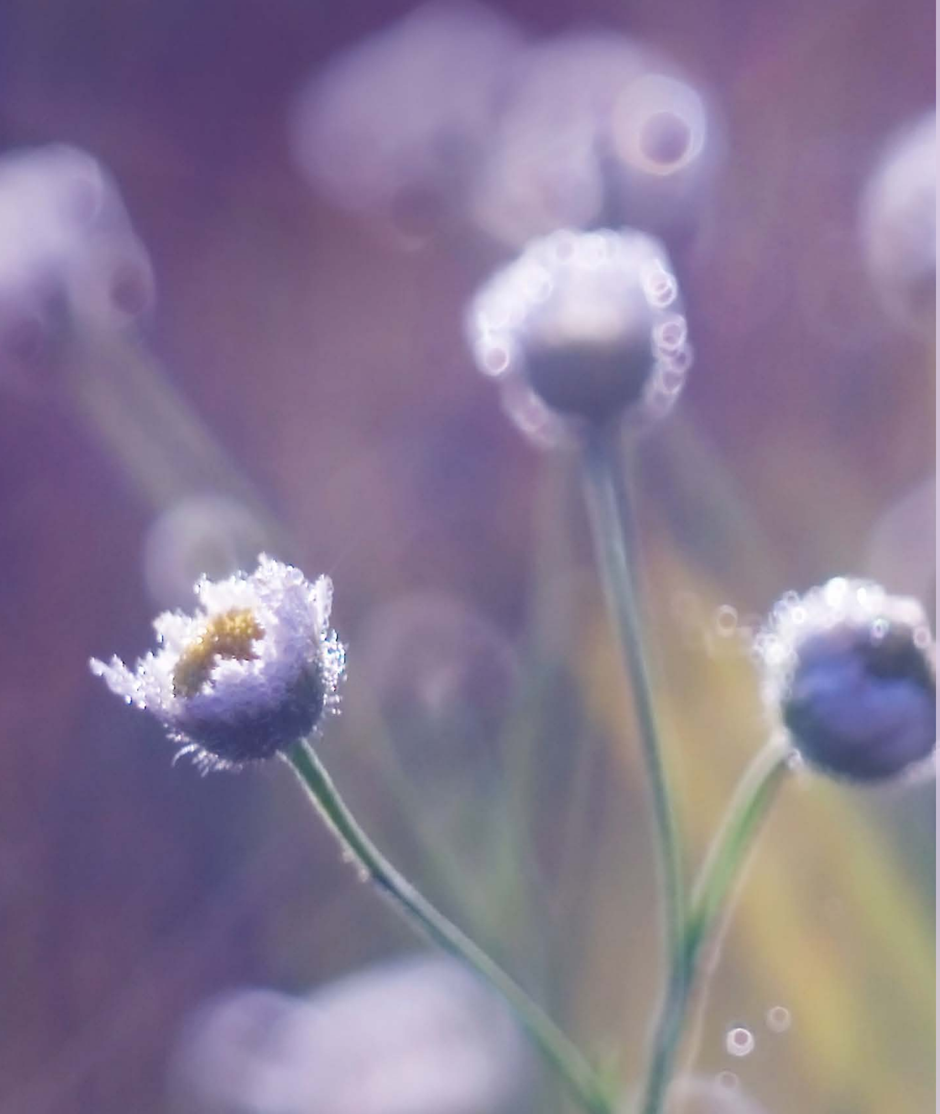
Pat and Tom's Story

PATIENT: Pat, died at age 73

CAUSE OF DEATH: Pancreatic cancer

REGION: Smiths Falls

CAREGIVER: Tom (husband)



Pat battled cancer for nearly nine years. When she was diagnosed the doctors led Tom, her husband, to believe that once she reached the stage where she only had one to two months left to live she'd be guaranteed 24 hour a day homecare support. He and their daughters were assured their time wouldn't be spent handling all of Pat's many medications or the administrative and medical tasks; rather, they would be able to focus on her.

That turned out not to be the case; and Tom felt he was left to care for Pat — who wanted to die at home — mostly by himself, during the last weeks of her life. In addition to having to manage her care, he also advocated on her behalf, working as hard as he could to respect her wishes and keep her out of hospital — even when the homecare nurses tried to get her admitted.

They never saw a case manager and didn't know what resources were available or where to find help. No one ever told them what CCAC resources were in their area. Tom described the services as "invisible, absolutely invisible."

Tom felt he had no one to turn to, with no doctors in the area who were interested in, or knowledgeable about caring for a palliative patient. The personal support workers and nurses didn't seem trained on how to handle the special needs of an end-of-life patient, or how to best help Tom provide his wife's care. "More services are needed during end-of-life — the maximum number of hours or visits available now per patient is just not enough. If a person prefers to die at home you must have the proper support system in place."

In the end Tom was able to ensure that Pat died at home. He says "the system needs someone families can turn to. Someone with the strength and knowledge to help them through this difficult process, because it's awful to lose a loved one. We are much better off spending our final days at home, but it can't be done without proper support."

Martina and Loren's Story

PATIENT:
Martina, died at age 82
CAUSE OF DEATH:
Colon cancer
REGION: Hamilton
CAREGIVER: Loren (daughter)

Martina was diagnosed with colon cancer in March 2012. Her oncologist at the Juravinski Cancer Centre was very reassuring and Martina's daughter, Loren, remembers "she had a warm way with my mother."

Even the fact that English was a second language for Martina, who was Slovenian, was handled compassionately. Both the doctor and pharmacist treating her made a special effort to speak slowly, ensuring Martina understood everything.

The plan was to manage Martina's pain as the disease progressed and to support the emotional issues arising from her diagnosis and prognosis with the help of a social worker.

Around January of 2013 Martina became very ill and her family required extra support to care for her at home. It was then that the "doors of palliative care were opened;" and they were relieved by how much support was available.

Loren remembers what a big difference the pharmacist made. "He assisted us with medication scheduling and always explained everything to us in great detail." He also communicated with the palliative care physician whenever it was necessary.

To this day Loren believes that "without the team, caring for my mother at home would have been impossible." The extra effort and support helped them manage the complicated medications and the encouragement they received always made them feel "like we were doing a good job."

The homecare nurses, who Loren describes as "amazing," were part of the support network Loren and her family relied on, as Martina was dying. And although some of the new nurses would unsuccessfully attempt to modify her mother's medication, the three nurses who visited regularly were a tremendous help.

Personal support workers not only cared for Martina, but made sure that Loren and her siblings knew exactly how to care for their mother, "because we wanted to participate and they made sure we could." And they were all there with their mother — as she wanted — when she died, at home.

Loren wishes she had known about what resources were available before they really needed them. "I wish I'd known about all the homecare and palliative care services earlier, it would have been a little less harrowing for my parents." Loren remembers the team she worked with fondly and believes "everyone, regardless of their first language or level of education, should have a health care provider who can communicate with them and is compassionate."

Fook Fook and Donald's Story

PATIENT: Fook Fook, died at age 76

CAUSE OF DEATH: Lung cancer

REGION: Toronto

CAREGIVER: Donald (husband)

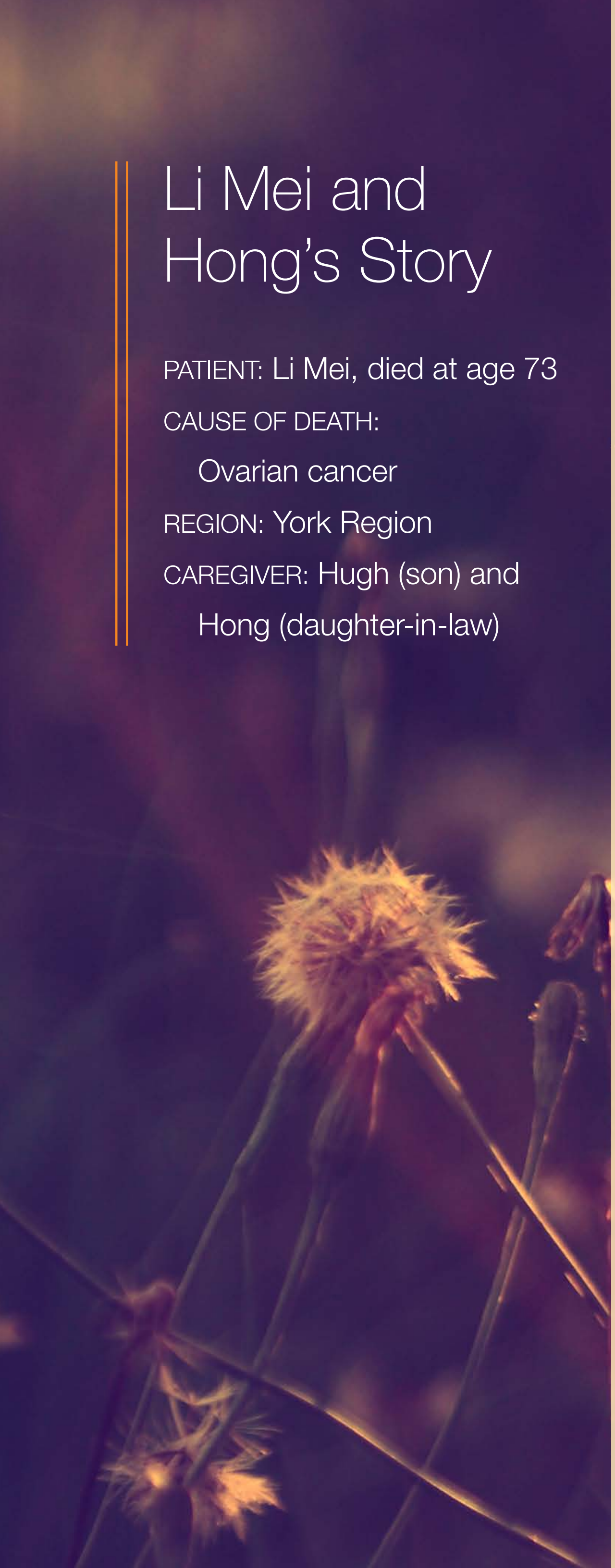
Fook Fook battled lung cancer for six years. Early on she tried to compliment her cancer treatment with holistic Chinese medicine, "thinking a type of mushroom pill would enhance her health." Neither she or her husband ever asked — nor were they told — whether or not these pills were compatible with the conventional treatment she was receiving; and, as it turned out, they worked against her radiation treatments.

After invasive surgeries, chemotherapy and more radiation Fook Fook was discharged and sent home, where Donald cared for her, for the eight months before she died. He was supported by both palliative care doctors and nurses. Two nurses, in particular, were a consistent source of support and the doctor, who came once a week initially, came more often as Fook Fook's condition deteriorated.

The medical care provided by the team was excellent but equally important, they were also sensitive to Fook Fook's wishes. When, for example, she refused more pain medication they respected that, even though they recommended the opposite.

As the cancer spread she became paralyzed and began suffering from bed sores. The ointment she was given didn't work and she had to be admitted to Princess Margaret Hospital. Donald recalls that "this might never have become an issue if we'd been told she should have been on an air bed, instead of a regular hospital bed." He also wishes there'd been more consistency in end-of-life care training among all her health care providers.

Fook Fook was discharged from the hospital and was able to pass, peacefully, at home. Donald felt supported and cared for by his wife's homecare team. He believes strongly in the importance of creating a positive environment for both the patient and the family. "Encourage the patient to think positively, but realistically. Be happy, enjoy whatever time is left."



Li Mei and Hong's Story

PATIENT: Li Mei, died at age 73

CAUSE OF DEATH:
Ovarian cancer

REGION: York Region

CAREGIVER: Hugh (son) and
Hong (daughter-in-law)

A nurse, herself, for 35 years, Li Mei was diagnosed with ovarian cancer at North York General Hospital. She battled the disease for three years.

Chemotherapy took a lot out of her and she became weaker and weaker and her family felt the trips to the hospital seemed to be doing more harm than good. This prompted them to keep asking, "What comes next? What should we do next?" And, as a result, as they cared for Li Mei they lived their lives "one day at a time, one hour at a time."

Li Mei and her family decided her last days would be spent at home but they were not prepared for how quickly that time would come.

They found and contacted Central CCAC, who were able to coordinate all of Li Mei's care. A hospital bed was delivered to her home and a palliative care doctor and nurse were assigned to provide pain management, medical and emotional care and support for everyone, including the family. Personal support workers helped with bathing and at this point, neither Li Mei's family doctor or oncologist were very involved.

Despite the regular assistance there remained many unknowns and Li Mei's family had many questions — most of which they had to "find answers to themselves." Yet when they were desperate for help, when they almost ran out of pain medication on Boxing Day, the team came through — and even though it was a holiday their prescription was refilled in time.

Li Mei died peacefully, at home, on New Year's Eve. Her family is grateful for the support they received, without which they couldn't have kept her there. Her care team showed true compassion and empathy and both Hugh and Hong believe that Li Mei, who cared for so many patients during her career, received the "best care possible" at the end of her life.

In hindsight, however, they wished there'd been better communication about the extent of palliative care available. They felt there'd been a gap between Li Mei's treatment stage and the palliative stage which they'd had to figure out for themselves — trying to advocate on Li Mei's behalf and navigate a system they knew nothing about at the same time. "There was so much I didn't know I needed — even right at the moment I needed it — and by the time I figured it out, it was kind of late in the game." They all believed it would have been really helpful if the treatment team had spent more time with them, answering questions and preparing them for what would come next.

Rob and Jennifer's Story

PATIENT: Rob, died at age 47

CAUSE OF DEATH:
Pancreatic cancer

REGION: London

CAREGIVER: Jennifer (wife)

Rob's family physician was the first to identify something might be amiss with Rob, an active and healthy 46 year old. Elevated liver enzymes raised concerns and Rob was sent for more tests. Symptoms of pain started to emerge and days after his CT scan, he was diagnosed with pancreatic cancer.

Navigating the health care system was difficult for Rob and Jennifer, even though they were both health care workers themselves. Once discharged from the hospital they didn't know where to turn. CCAC arranged for nurses to come to their home a few times a week. But, because they weren't much help at that, particular, stage of Rob's journey, Jennifer discontinued the service.

As the weeks wore on they didn't seek out much professional help other than the palliative care physician who'd been assigned when Rob was diagnosed.

Jennifer was left, on her own, to sort out disability and drug coverage and manage all of Rob's increasing pain medications. But as Rob's care became more complicated she connected with the Southwest CCAC Palliative Care team.

Given their careers in health care, Rob and Jennifer were comfortable working with members of their palliative care team; and together they determined with which team members they worked best. Their physician, spiritual care specialist, and nurse practitioner were "amazing." This was in stark contrast to the oncology clinic, where staff were busy and made them feel as if they were "one of many" — never really affording them the time to discuss their options or ask questions.

Jennifer felt the oncologist was disconnected from Rob's homecare team. On occasion, for example, the palliative care doctor and oncologist would prescribe contradictory treatment plans.

Rob and Jennifer took a very proactive, focused approach to his care. For instance, they made their palliative care nurse practitioner their point person, charging her with the task of referring them to the right people. "I, [Jennifer], would report any change in symptoms to her and then she, in turn, would consult with the necessary team member(s) and then let me know what changes to make."

Thanks to the palliative care team, and in particular their nurse practitioner, Rob's pain and symptom management was "exceptionally well managed." All of Rob's care, aside from chemotherapy, was handled at home, making his death "less scary."

Jennifer says it best herself:
"Primary caregivers are capable of a huge amount and it can be so rewarding to take care of someone you love when they're dying. It's something so incredibly difficult I would never, in a million years, regret doing. I think caregivers can do a lot more than what we give them credit for, but I think we need the tools to do it, we need the right support, we need timely access... because things change so quickly in palliative care."

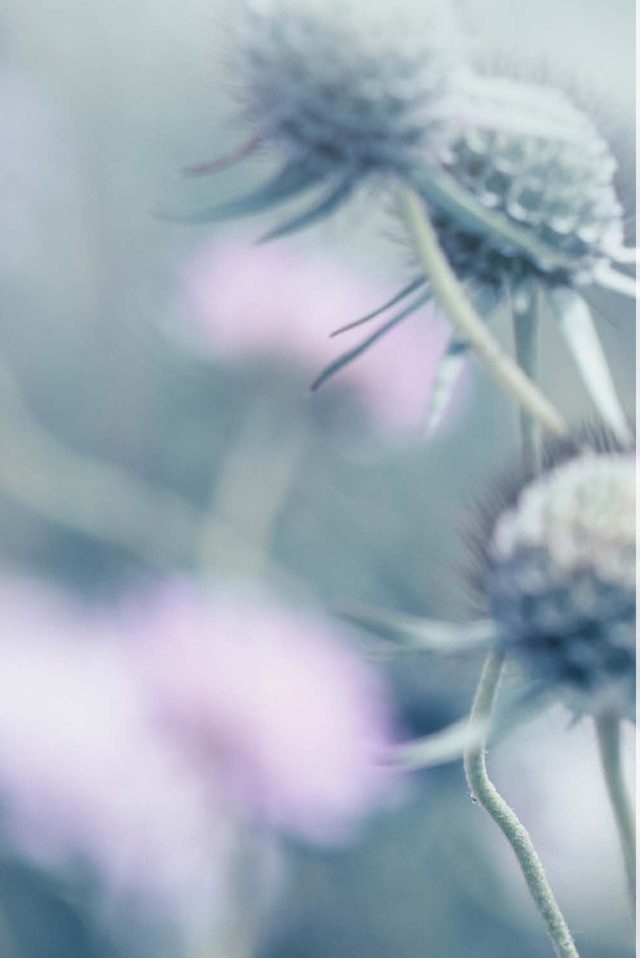
Mildred and Joy's Story

PATIENT: Mildred, died at age 97

CAUSE OF DEATH:
Congestive Heart Failure

REGION: Toronto

CAREGIVER: Joy (daughter)
and family



When Mildred was diagnosed with congestive heart failure, she was informed she had about six months left to live. Her family doctor suggested palliative treatment.

Given her age, Mildred had already started to rely on personal support workers for chores around the house. With this new diagnosis, however, her children knew they would need more nursing and personal support workers to help care for their mother — and honour her wish to stay out of a nursing home. As the palliative care team took over, Mildred's family physician was no longer involved.

Dealing with the CCAC was difficult for the family. They never really knew who their case manager was, and found that communication between CCAC and other services, like the Red Cross, was poor. The family also felt the "available services were not necessarily what Mildred needed." A major issue being the "prescribed tasks" the personal support workers were allowed to do — which didn't include time outside or a simple walk, activities Mildred truly needed and wanted.

As a result, in the end, at their own expense, the family hired nurses from outside providers to supplement what the CCAC couldn't cover. "Problem with CCAC is everybody wants them [CCAC services] all the time, and there will never be enough money in the system to provide that."

As her death drew near, the palliative care physician visited the house every week and, then, every day. The nurses who cared for Mildred remained fairly consistent, but mostly she was cared for by family. Joy mentioned she would have liked to have "more training for herself and other caregivers on the basic care, like how to turn her mother in bed, to prevent bed sores."

CCAC provided equipment to aid their mother's comfort as her health deteriorated — a hospital bed, a chair to help her stand and other needed items. Specialists came in to teach Mildred exercises to keep up her strength and, as her needs changed the CCAC did what they could to appropriately support her family, like changing the personal support workers' schedule. "CCAC was responsive to my mom and to us whenever it was possible."

Mildred was active almost right up to the week before she died, visiting people and being out and about. Having suffered from chronic pain almost her entire adult life, Mildred died, pain free, at home, cared for by family and supported by the homecare team.

When All is Said and Done

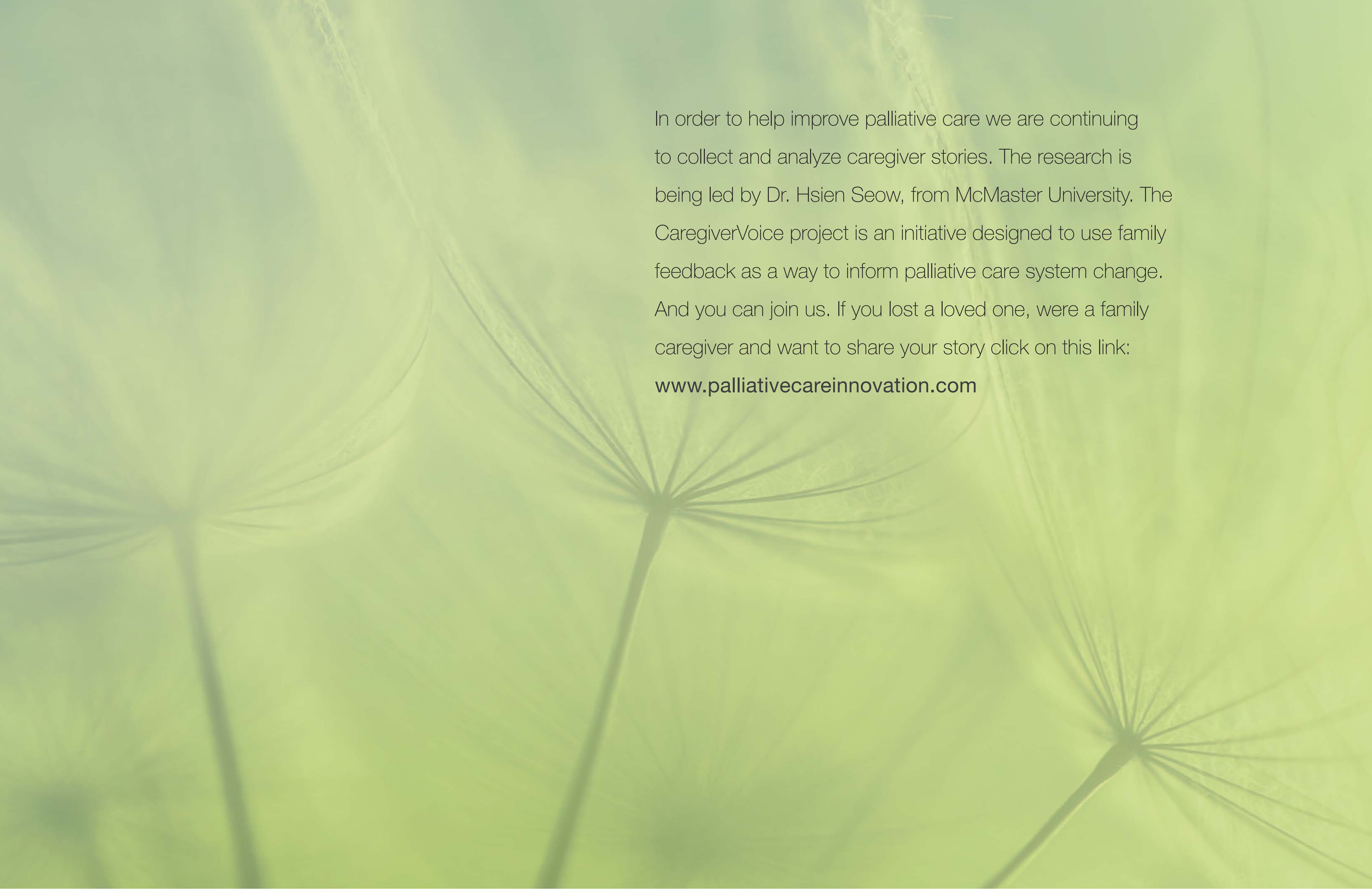
In reading these stories, what you've 'heard' are the voices of the spouses, sons and daughters who cared for their loved ones, at the end of their lives, in their homes. They all used the care support available in their communities in different ways and, to different extents. A diversity of experiences have been presented. However, even among the variety of families with whom we connected, there were some very specific, and similar, issues which emerged.

While some of the experiences left the caregivers with a more positive impression, for most there were both good and bad aspects to the care and support they received. Strikingly, many caregivers felt their loved one's final decline came very quickly; and often they recalled either being unprepared, or that it took too long for the services to start.

The most prominent theme that emerged is the lack of information provided. This runs the gamut from educating caregivers on how to help care for the patient and what to expect, to knowing who to call when help is needed and what services are available. Consistently the caregivers highly valued those providers who were both compassionate and knowledgeable in end-of-life care.

Fairly often, one or more champion providers were identified as excelling in their particular area of support. This dedication gave confidence to the patients and caregivers, helping to reduce their anxiety. In some instances they felt as if there was a 'circle of support' around them, because of how seamlessly the various providers worked together. In contrast, in some cases while services were available, they were not accessed effectively, if at all, because of the breakdowns in communication between the various providers.

Rarely was every part of these personal experiences of palliative care terrible — but, as these stories reveal, there is still work to be done.



In order to help improve palliative care we are continuing to collect and analyze caregiver stories. The research is being led by Dr. Hsien Seow, from McMaster University. The CaregiverVoice project is an initiative designed to use family feedback as a way to inform palliative care system change. And you can join us. If you lost a loved one, were a family caregiver and want to share your story click on this link: www.palliativecareinnovation.com

For more information about the research study into community-based palliative care, please visit our website at: www.palliativecareinnovation.com

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