

PL-3-14 Lorraine Kember

Presentation by the Author of “Lean on Me” Cancer Through a Carer’s Eyes

Lorraine Kember

We have come together today, in the knowledge that asbestos is a killer, a grim reaper of innocent lives. We hear about it on the radio, watch those affected by it on the television and fear for our own lives – for there are few of us, who have not been exposed to asbestos, or to products made from asbestos, at some time during our lives. No consolation is to be found with the passing of time. We now know that many years may pass between the inhalation of asbestos dust and its deadly legacy of mesothelioma. Tragically, there is an ever growing list of those killed by asbestos; there is no list however, of those who are wounded because of it. I speak of the countless wives; husbands, parents, children, grandchildren, family members and friends, who have had to bear witness to the physical devastation caused by mesothelioma and the resulting death of their loved ones. This catastrophic experience wounds deeply and the scars remain for a lifetime. I stand before you today as one of the wounded. We are united in our quest to rid the poison of asbestos from our environments and in our hope of finding a cure for mesothelioma, so that we and future generations may be spared the devastation of this and other asbestos related diseases. The fact remains however, that there are many who are suffering now and many more who will suffer and die in the future, before our dream of a cure is realised.

Mesothelioma strikes without warning; my husband was an incredibly strong and virile man, who had rarely experienced a sick day in his life. When at the age of 52, he suddenly began to experience shortness of breath, we thought it most likely due to a chest infection and made a doctor’s appointment expecting that he would be given a course of antibiotics. Instead he was given the death sentence of mesothelioma. Although I was aware that Brian had spent 7 months as a child in the asbestos mining town of Wittenoom, I found it almost impossible to believe that the asbestos dust he inhaled then, had taken 45 years to become lethal. There is nothing that can prepare you for the shock and devastation of a terminal diagnosis. When Brian received his, I felt as if we had both been shot and I saw his prognosis of three to nine months, as a time in which we were expected to drop.

I cannot imagine the torment Brian must have endured living in expectation of his death. I can portray the catastrophic effect his illness and impending death had on my

life. Upon hearing his diagnosis, my initial shock was followed by anger and denial. I refused to believe that there was nothing that could be done to save him and began searching the internet for any information regarding mesothelioma, hoping to find someone, somewhere who had found a cure for this terrible disease. I was searching for a miracle and found none – however the knowledge I acquired, helped me to accept that my husband was dying. This did not make it easier to bear. Living in expectation of your loved ones death is like sitting on a time bomb, knowing that it is going to go off and being powerless to stop it.

There were so many frightening and un-answered questions. Would we be granted 90 days, 270 days or somewhere in-between? We dared not plan for anything fearing that Brian would not be with us to enjoy it. With no idea of what to expect I feared he might die at any time and saw any symptom he displayed as a sign of his imminent death. I was reluctant to let him out of my sight for fear he would not return to me and dreaded the beginning of each new month, as it brought us ever closer to the maximum time given for his prognosis. My emotional turmoil soon affected my health, I ached with tension, began to have trouble catching my breath, groaned involuntarily and felt as if I too were dying. For the first time in our long relationship, I could not turn to Brian for strength, nor could I burden the children with my grief; they had not fully accepted their father's prognosis and it hurt them if I mentioned his condition. It was hard to remain strong for all of them and to act as if everything was okay – when nothing was okay. Despite the fact that Brian was surviving past his prognosis, I remained in acceptance of his impending death and came to realise that he alternated between acceptance and denial of his fate. I recognised and supported Brian's need to live in hope – whilst at the same time I was struggling with my hopelessness. My anticipatory grief often overwhelmed me, there were days when I told everyone I met – that my husband was dying. Seeing the sympathy and compassion on their faces, justified the depth of my despair. On my doctors advice I began keeping a personal diary; this became my strongest coping tool. I wrote in it daily, pouring my heartache and fear onto the pages often in the form of poetry. I wrote the poem "Loving You" shortly after Brian's was diagnosed, the words "Lean on Me" later became the title of my book.

Not long after Brian's diagnosis, I observed that despite his medication, he was in considerable pain and this upset me greatly - determined to help him, I once again turned to the internet- this time to learn about the progressive symptoms of mesothelioma - the pain he would experience - and methods available to control it. In this way, I came to understand, that although I could not stop my husband from dying – *I could help him to live*. One of the most important things I learned, was that in order to obtain the best possible pain control – medication must be taken at regular prescribed times, regardless of whether pain is or isn't present, effectively keeping in front of the pain. I learned that there are different types of pain and that not all pain responds to the same medication; and how to measure intensity of pain and

encouraged Brian to communicate to me - the type of pain he was experiencing and its intensity using a pain scale of 0 to 10. Brian soon realized the benefits of this - It was an immense relief for him- to know that I understood what he was experiencing and more importantly – that I could do something about it. I also began keeping a daily journal in which I listed the various medications Brian relied on, the times they were to be taken and their dosage. In this journal, I also recorded any break through pain he experienced careful to describe its type and intensity. Any symptoms Brian experienced both due to the progression of his disease and the side effects of the medication were also recorded. I took my journal with me on every visit to the doctor, my records enabling him to easily assess how Brian was coping with his disease and provided the means by which to accurately determine the strength of medication needed, to bring Brian’s pain and symptoms back into control. To Brian’s immense relief his initial nausea due to chemotherapy and constipation due to medication was also able to be controlled.

Chronic untreated pain is debilitating, it dramatically affects a patient’s ability to participate in daily routines and in some cases takes away their will to live. Through my experience and the knowledge I have acquired, I have come to realize that many people are suffering chronic pain unnecessarily. This is, in part, due to them not being made aware of the importance of pain management and being shown the simple tools necessary to achieve it. Lack of knowledge regarding the benefits and side effects of available medication is also a factor. Many patients associate morphine and methadone with drug addiction and are reluctant to take it due to their belief that it will cause them to become “high” or sedated, this and their attempts to brave out the pain, result in their pain spiralling out of control. This could be prevented if they were informed that chronic pain effectively “uses up” medication and that these drugs when taken for the relief of pain associated with cancer, can dramatically reduce both the occurrence and intensity of pain, without causing sedation.

Testament to this, despite the large amount of methadone Brian was taking; he remained active and alert, drove his car for eighteen months after diagnosis and was able to continue going fishing, which was the passion of his life. Keeping him out of pain became the reason for my existence and I was vigilant in giving him his medication at prescribed times. There were many occasions when caring but uninformed loved ones and friends, said to me. “Brian does not need for you to be giving him medication at this time – he is not in pain”. And I would patiently explain to them, that the reason Brian was not in pain, was because the regular medication he was receiving effectively allowed for him to remain in front of it. As Brian’s disease progressed, there were times when his pain broke through his stable medication; however, due to our good communication and the use of hydromorphone; we were able to bring it back into control within a short time.

Experience has taught me that knowledge is the key, to better quality of life, not only for the mesothelioma patient but for those who care for them. My understanding of the stages and symptoms of mesothelioma, allowed for me to be one step ahead of its progression and gave me the opportunity to have medication and later, physical aids such as oxygen, wheelchair etc – on hand **BEFORE** Brian needed them. This alleviated much of the fear, pain and discomfort he would otherwise have suffered. I believe that all patients and their carers must be encouraged to talk to their doctors about the progressive symptoms of mesothelioma, so that informed choices can be made regarding available treatment and medications. It is important for health professionals to realize and support a family's need to maintain some control over their lives, this removes their sense of helplessness, gives them purpose and helps them to cope with the anticipatory grief associated with terminal diagnosis.

Brian was not bed bound until three short days prior to his death. As was our wish, he passed away at home surrounded and supported by all of his loved ones. Through this, I have found much peace.

I have written my book in the sincere hope that it will inspire others to take an active role in the care of their loved ones and that they too find peace in the knowledge that they made a difference. Through words, we touch the hearts of others. I have received many wonderful letters from readers, thanking me for sharing my experience and emotions with them, they tell me that my diary excerpts and poems have helped them to identify with their own emotions and opened up lines of communication with loved ones and friends. I am humbled by these letters. It is wonderful to know, that through my book *Lean on Me*, Brian will live on and that together he and I are helping others.

I wish to thank the Mr Sugio Furuya for inviting me to speak today and to thank everyone who has been involved in making this GAC Congress both a worthwhile and memorable experience.

Thank you ladies and Gentlemen