

### Ken's Story... November 2021

Ken's Story... In February 2020 my wife Margaret, had a sickness bug that she couldn't shift, prior to that she had been fit and well. Then in March 2020 she noticed changes in her skin condition, Lichen Sclerosis, which she had had since her 40's and which had been managed by steroid cream - the area had now become painful and a lump had appeared. Lichen Sclerosis is a gynaecological skin condition that affects the intimate parts of the male and female anatomy.

It took a while to get an appointment with her GP because of the COVID outbreak, but on her first visit she was prescribed another course of steroid cream. However, Margaret's symptoms persisted and a further GP appointment was made, it was at this time Margaret received the devastating news that her GP suspected the lichen sclerosis had developed into vulva cancer. She was referred to a specialist who confirmed the diagnosis and on 20<sup>th</sup> May, she had radical surgery to remove the affected area which also involved removing the lymph nodes in her groin. Margaret's recovery from the operation went well and she commenced Radiotherapy in August, but around October we noticed Margaret was losing weight, looked very slim and her energy levels had dropped. Further scans on 20<sup>th</sup> November revealed that the cancer had spread and we received the devastating news that Margaret's condition was now palliative.

At first we cared for Margaret on our own at home because our daughter Eleanor wanted to manage the personal care for her mum - she thought it was important to allow me to be able to continue to be her husband and not her carer. Eleanor was also incredibly protective of her mum's dignity given the sensitive nature of her condition. Our sons Chris and David were a huge support at this time with physical and emotional care but we needed professional advice on how to help Margaret physically. However, as Margaret's condition deteriorated it was becoming increasingly difficult to manage on our own.

It was when Eleanor took a call from the consultant to inform us that a recent scan showed that the cancer had spread to Margaret's lungs that Eleanor said ***'we need help because mum is in pain and unable to get out of bed.'*** It was the District Nurse who suggested we ask **HospiceCare North Northumberland** for help which initially we all felt apprehensive about having someone else care for Margaret, but we also knew that we had reached the point that we needed to accept help. After the District Nurse referred us to **HospiceCare** their Clinical Services Manager, Nina, telephoned us to talk through how they could help and support us which then reassured us all and enabled Eleanor, Chris and David to be her children again and not her carers.

From the moment **HospiceCare's Hospice at Home team** arrived we felt totally at ease, we asked lots of questions and shared our concerns but nothing phased them, nothing was too much trouble and we never felt rushed. From initially being apprehensive about having help for Margaret, we quickly felt we had done the right thing and that **HospiceCare** had taken a huge weight off our shoulders. The Healthcare Assistants understood what Margaret needed and when. Even when we were no longer able to understand what Margaret was saying because she was so poorly, the Hospice at Home team did. They took time to understand our needs as a family and the way in which we wanted Margaret to be cared for, we always felt respected, valued and listened to.

Whilst they took over the personal care for Margaret they allowed Eleanor to continue being the reassuring voice to her mum so that she felt it was her doing the tasks. Sometimes, it was the little things that had the most impact such as suggesting we put some music on for Margaret to listen to some of her favourite tunes, which gave us much-needed family time as well as light-hearted moments sharing family memories attached to each song.

The Healthcare Assistants would use Margaret's hand cream, face cream and favourite perfume which made her smell lovely and in Eleanor's words **"like mum again"** - they would change the bedding so that Margaret's room always smelt clean and fresh. Being at home also meant I was able to lay with Margaret to hug and reassure her in those final days knowing that the Hospice at Home Healthcare Assistant was discretely around for support if needed.

On the days leading up to her death we were all able to have special times with Margaret which was only made possible because she was at home with us, like the time David told his mum that he had found love and was able to proudly show her images of his fiancée, it was a special, now treasured, moment between the two of them. During this time our extended family also got to say 'goodbye' to Margaret, sharing their stories and plans for the future with her. Having Margaret at home allowed me and our children to spend unlimited time together in a space where we felt safe and loved – our family home. We always felt supported by HospiceCare because they gave us an 'open door' for the smallest concerns and travelled a huge amount of miles just to be there for us and for Margaret.

We didn't notice any change in Margaret's condition but there was a point when the Healthcare Assistant recognised her condition had changed albeit so subtly, but I remember her saying **"I think we are very near and should get all the family together."** The Healthcare Assistant then quietly left the room to allow us to be together. Margaret died peacefully on 5<sup>th</sup> December 2020 at home, in her own bed, with her family by her side, which was her wish – and ours.

She was just 64 years old and we miss her, so much. I think it's an imperative part of end-of-life that needs are met. The impact of HospiceCare's support on our lives is immeasurable because not only did they care for Margaret in the way we wished and met our family needs, they also gave us support and comfort at an incredibly scary and traumatic time. We had

previously reassured Margaret that she wouldn't go back into hospital so not only did HospiceCare's support allow us to fulfil this wish, they have also enabled us to create beautiful family memories – ones that we will hold in our hearts for the rest of our lives and for that, we can't ever thank them enough. Ken, Eleanor, Chris and David.