

Emma's Story

Hello Everybody,

My name is Emma, I'm 47 years old and a mother to four daughters.

I was the sole carer to my mother Janet for 19 years until her death in January 2019 from three grade 4 pressure ulcers that she developed after a three week stay in hospital.

My mother was 80 years young when she died but so much younger than her years.

She was paralysed from the waist down after a spinal stroke 20 years previously and over the years she had both her legs amputated due to various problems, but she never let it get her down. She was always so upbeat and an inspiration to us all.

We weren't just mother and daughter she was my best friend and we were so close as we spent so much time together that we were like one person, she never left the house without me being with her.

We were a team, I made sure I gave her enough independence to give her the confidence that she could do anything herself, but I was always right there beside her like her safety net.

I took my mother out in the car everyday and we were very well known in our local area and further afield in other towns and cities, anywhere for a change of scenery. We got to know all the locals in the different areas, they still ask after her now when I go to those places.

I suppose we were quite an odd sight, my mother in a wheelchair without legs, lippy on and hair done to perfection and then there's me a tall blonde tottering in heels pushing her haha.

She had a fantastic outlook on life and would listen and help anyone. She had time for all and would help people see that there's always someone much worse off and there a solution to every problem.

Throughout my mother's life we were always very

aware of pressure and the problem it can cause.

At home she had all the correct pressure relieving equipment (mattress and wheelchair cushion), commode etc. and I made sure her skin was checked and moisturised daily. In my care she never developed any pressure ulcers. If SSKIN guidance is followed it is the best preventative as we all know it takes only a few hours for a pressure ulcer to develop yet it takes weeks, even months to heal them.

Life changed drastically for my mother and me after she developed the pressure ulcers in Aug 2017.

[As a result of the pressure ulcer] she was in pain. Even though mum was paralysed she still had touch sensation and the pressure ulcer made her very snappy, irritable and she would cry which was heart breaking.

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Before the pressure sores my mother was very sociable but when she developed the pressure sores she had to relieve the pressure in that area which meant a lot of bed rest which gave her a non-existent life.

We were very fortunate to have understanding district and tissue viability nurses who worked with us to give my mother a happy balance or she would have just given up.

Having pressure sores made her appetite very low so I had to think of



ways to get the most nutrients in her in small amounts, so because she didn't like milk I'd put her Aymes shake in angel delight so she didn't know and I'd make her omelettes for protein... all the time thinking of new ways to get her appetite better.



My mother's pressure sores were extreme as osteomyelitis (bone infection) had infected the bone through the open wounds and this is an added

complication [of pressure ulcers] that not many people are aware can happen.

The dressings were changed twice a day on a good day but mostly at least 3-4 times daily which was impossible for the district nurses to attend so I worked with them and changed the dressings even learning how to apply a special vacuum wound dressing therapy.

My life for a year and a half was changing dressings 3-4 times a day while becoming numb to the horrific sights of the pressure sores, then trying to get nutrition in her and fluids and trying to boost her self-esteem and mood as it can all get very depressing at times.

As things deteriorated all her strength had gone and she relied totally on me. I went into auto pilot and moved in to my mums so I was there for her 24/7 so my daughters and nephew would come and relieve me for a few hours so I could go to the gym as I myself have multiple sclerosis and needed not to stress in order to keep my condition from relapsing and a few hrs in the gym did the trick for me.



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After a hard battle, the pressure sores became horrific, exposing the hip bone, something nobody should have to experience or see let alone your loved one but I'd have done anything for her as I'm sure we all would for our mothers.

She died peacefully at home holding my hand. it's left a big hole in my life as it does for anyone that loses a loved one.

For a long while I felt a heavy guilt weighing me down as if I didn't do enough to fix things and make it go away even though I knew

I did everything and more to save her ... it's strange all the things that go through our heads in times of grief.

One thing that did strike me though is how lonely it can be

for a carer after a loved one has died as carers are quite isolated especially when caring for a family member as all their time goes on care leaving no time for friends or socialising.

I was lucky to have great support from my four daughters and a small handful of friends, the district nurses were a wonderful support also.

Pressure ulcers took away my mother's life far too soon and changed mine and my family's life completely.

I'm soon to become a grandma twice over. It's sad that my mother won't ever get the joy of meeting them, but I still feel her with me in everything I do.

Many thanks for reading my story and I hope it's helped highlight the seriousness of pressure and the devastating effects it can cause.



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#StopPressureUlcers

#lovegreatskin

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Talley
...reducing avoidable harms