

Bounce Back Betty's story May 2023

Service name: Home Enteral Nutrition (HEN) Dietetic Team

Main purpose of service: The HEN dietetic team, work with patients and their families, ensuring that people who need to be fed via a feeding tube, experience safe and effective feeding in the community. HEN is short for 'Home Enteral Nutrition'.

Introducing Betty

Betty, known to many who knew her as 'Bounce Back Betty', passed away in April 2023. Betty's daughter Kay met with Joanne from Locala's Engagement Team to share her Mum's story.

Betty was diagnosed with Multiple Sclerosis in her early 50s and with determination and a zest for life, Betty remained committed to doing what she could, whilst she could. Meeting her beloved husband Eric as teenagers in Calderdale, the couple often went dancing, impressing many with their Rock 'n' Roll moves! They married in 1962. They were married for 61 years.



Betty and Eric shared a 'can do' attitude and a determination to stay as well as possible for as long as they could. They took part in daily exercises to keep mind and body fit and well. They learned to speak French and Spanish, and Betty became an accomplished artist. Her huge embroidery pieces adorn most of her family's walls. They travelled extensively. Even as Betty's mobility reduced, and she needed her wheelchair most of the time, they travelled to the Southern Hemisphere and fell in love with New Zealand.

After many years living near Blackpool, Betty and Eric returned to West Yorkshire and moved to Huddersfield in 2014. In 2015, Betty, Eric and Kay went backpacking in New Zealand for 10 weeks, touring both north and south islands and staying in Youth Hostels. They visited Australia and snorkelled on the Great Barrier Reef.

In June 2019, Betty became seriously poorly and was admitted to hospital. She was there for 4 weeks. Before this incident, Betty could independently move from her wheelchair to her bed, or the toilet, and she could get herself in and out of bed. Kay takes up the story. **"After travelling, I had actually moved to Australia and was living there. I had a successful job and a lovely life. I flew home, as we were told to expect the worst for Mum. But Betty had other ideas and she fought for herself and her health improved – the doctors said she was miraculous. She never fully recovered from the relapse and when she was discharged, she had lost a lot of her strength, she came home with a catheter, a hospital bed and she needed hoisting most days."**

A privately funded part time carer was arranged. Kay went back to Australia. The carer came twice a day to get Betty up and to put her to bed. Betty's needs were far reaching, and Eric and their son David were on call constantly for her. David gave up his job as a lecturer at Wakefield college and started working part time, as a supply teacher in Huddersfield, so he could be closer to them when they needed him. Betty had several bouts of severe UTI's (urine infections) from the catheter and she was constantly on antibiotics. The infections took hold of her very quickly, and she would become delirious quite rapidly **"I got to the point even from so far away where I could tell from Mum's texts if she was getting poorly."**

Kay tried to help as much as she could long distance. Time differences made phone calls difficult. By November 2019, Betty was back in hospital again. By chance, Kay was visiting the UK to celebrate her birthday. Kay explains, **“It was then that I started to get more involved in Mum’s care. I spent a lot of time with her whilst she was in hospital. We were all deeply invested in Mum’s care and being with her for such a long period of time meant I became familiar with the changes in her physically and mentally. Although I didn’t realise it until much later, I became her advocate. I delayed my return to Australia and eventually stayed 3 months instead of the 3 weeks I was supposed to.”**

After 5 weeks of hospital care, Betty came home. January 2020 saw the start of renovations to the house and there was a fully adapted extension built on the side of the house. It was built for Betty’s needs, being wheelchair friendly and with ceiling hoists. It was a big commitment from all the family, funded from family money.

Kay returned to Australia and during the next 5 weeks, Betty was admitted to hospital a further 2 times. Kay explains, **“I realised at that point that everyone was exhausted with Mum’s continuing and developing needs. David was trying to work and help care for Mum and Dad was stressed to a point that was becoming unhealthy. I made a decision I was needed in the UK to be with them, and within days I had left my job, and my partner and was flying back. It was March 16th. Lockdown had started. Places were going into lockdown behind me as my planes took off! If I hadn’t been on that flight, I wouldn’t have been able to get back. It was weird – either airports were like ghost towns or were very busy and madness! I isolated for 2 weeks then moved in with Mum and Dad.”**

Kay imagined she would be back in Australia 10 weeks later, but she has been in Huddersfield for 3 years.

Becoming a carer

Kay says, **“I had to be there for Mum, for all of us as a family. Because of lockdown and shielding I became her full time carer. I learnt so much in such a short time. It was a heartbreaking, challenging but beautiful time. The relationship between the three of us flourished, and we created an even greater love, trust and friendship that cannot ever be replaced. Dad had always been very involved with Mum’s care. He was always insistent she did her physio and speech language exercises every day. I was with her so much I learn to spot what was going on with her, to understand when she was becoming poorly – usually UTIs. I got to understand when she was becoming delirious.”**



Betty was admitted to hospital on multiple occasions during the rest of her life. The hardest times being through lockdown. Kay began to understand the system during lockdown and was able to persuade medics to allow her to be with Betty during the worst of her deliriums. **“She was admitted to hospital in such a bad way, she didn’t even know what was happening, she was incapable of understanding anything, how was she supposed to represent herself? I was desperate for the staff who were caring for her to know that she was a feisty, wonderful woman locked into a body that kept trying to kill her, that she wasn’t the woman they saw when she was admitted. That she deserved every chance they could give her.”**

Kay consents to Betty’s story being shared widely.

On one occasion Betty had an episode of delirium which lasted 4 days without either of them sleeping. Betty continuously recited the Lord's prayer and sang. Kay says, **'The staff at the hospital were wonderful with both of us, supportive and encouraging, and as they saw her fight they always stepped up and dedicated themselves to her even more.'** This happened on every occasion she was admitted as urine infections led to chest infections and pneumonia. Betty had sepsis on several occasions and often the family were warned to prepare themselves for the worst outcome. But, Bounce Back Betty always had other ideas! She fought her way back to health time and time again.

The family learnt how to do 'suction' to help Betty's chest when she was discharged home with non-invasive positive pressure ventilation, known as a 'NIPPY ventilator'. She used it twice a day without fail.

Then in December 2020, Eric was diagnosed with Stage 4 bowel cancer and needed surgery. He then had a stroke. Because of the continuing lockdown rules, there were limits on who could come into the house, so Kay became Eric's carer too. David helped where he could, but with a full-time job and a family of his own, it was hard for him to be able to help as much as he wanted. Kay remembers, **"At one point because Dad was so frail and Mum still needed her care, it was easier to all sleep in the same room. At one point we had 3 beds in Mum's room, we were like the 3 bears!"**

Kay continues, **"I was an advocate for both Mum and Dad. I pushed and pushed to get the best help I could for them. Everyone was working under immense amounts of pressure, but I would not accept anything but the very best for my parents. Persistence, being understanding of the professional's pressure, but being actively involved with all aspects of the provision of their care. I was polite but I never took 'no' for an answer. I learnt that if you don't push, you don't get."**

One of the successes of Kay's tenacious approach was to eventually receive full 'Continuing Health Care' funding for Betty's care. Kay feels that the role of unpaid carer is all consuming. **"Looking after Mum and Dad was the only thing I could think about or talk about. It becomes your life."**

Kay explains that as Betty's NHS funding meant they could employ an agency to care for Betty, she met lots of new people and had new influences in her life. Betty thrived for a while and had 47 weeks without any hospital admissions. Betty loved people and now she had new ones to meet and understand. Her carers became her best friends, there was always laughter and music in the house. **"The carers also became enthralled with Betty's loveliness and determination, they gave her an immense amount of care and respect. They also gave her another level of mischief and she decided she wanted her hair pink. Of course, she got her way, she looked amazing and with the additional benefit of making sure she would be known and recognised as an individual, not just the patient in bed 20."**

Bouncing back...again...and again...and again:

Kay talks about how her Mum earned the nick name Bounce Back Betty. **"She has been at death's door more times! Each time she fought her way back, it wasn't without immense amount of determination and courage though, but every time she came home from hospital she was a little frailer. The stamina she had! Whenever she was asked to do something for herself she would always say, 'I'll try'. She was so determined. We all worked as a team, family, carers, 'Carers Count' sitters - all became Team BBB. We became expert in spotting her symptoms and because of that, we managed to get her into hospital for the treatment she needed long before the drama of her deliriums starting. This was a blessing and a curse because for the first time she began to be conscious of how poorly she was. There would be times when I was with her in hospital**

Kay consents to Betty's story being shared widely.

and she would ask me if she was dying. I assured her she wasn't, that she had been in such worse states, but she didn't know that. I asked her why she was scared of dying and she said, 'I'm not scared for myself I just don't want to leave you all, how will you manage?'. She wanted to live on for her family."

As she got weaker, Betty's body became less able to function, her swallow reflex became very poor and she had several bouts of aspiration pneumonia. At one point, while Kay was travelling in Europe, Betty was admitted back into hospital. **"She was very poorly, almost comatose, however for some reason the doctor in charge of her care decided to send her home as 'feed at risk' even though it was known that her weak swallow meant it was fatal."** During a telephone conversation with the doctor, Kay remembers insisting that **"sending Betty home in that way would mean she would be dead in days and that Betty needed to be fed, all she needed was the correct care, that the woman the doctor was technically writing off wasn't ready for that yet."**



Kay requested, with the support of Betty's Speech and Language Therapist, that Betty be tube fed. Kay recalls, **"The Speech and Language Therapist rang me while I was in Greece. She was puzzled because Mum was in hospital again and I wasn't with her – another benefit of having pink hair – it was the therapist that remembered how well Mum had recovered with an NG (Naso Gastric) tube**

in the past, and we worked together to convince the doctor to give Mum another chance. He gave her 48 hours to begin recovery or said he would send her home, effectively to die. I told him that would be all she needed. Within 24 hours, he called me back to inform me Mum had improved so well, they were keeping her in hospital and beginning investigations into her swallow and possible solutions. She was eventually fitted with a PEG (Percutaneous Endoscopic Gastrostomy). She seemed to do quite well with it at first."

Kay continues, **"Because I couldn't be there with her and advocate for her, I was desperate to find a way to represent her in some way, so everyone understood who she was. As a consequence, we printed a colour photo of Mum in her finest frock and denim jacket, smiling her beaming smile. We put a note underneath it with the title 'Bounce Back Betty' and it said 'When I'm not poorly I am a right character. I am funny and loving and I love life.' We stuck it above her bed. There are some people in the medical profession who are too quick to write off elderly, poorly people. You have to remind them that there is a person behind that suffering, that how they are today when they are so sick, is often not WHO they are when they're well!"**



Kay says that 'Team Bounce Back Betty' included her GPs, their receptionists, the many carers, sitters and all the other health care professionals, friends and family that did their best for Betty. Everyone wanted the best for her.

Kay consents to Betty's story being shared widely.

Locala's HEN team

Thinking about Helen, Betty's dietitian, Kay says, **"Helen was amazing and dedicated and went above and beyond. My Mum became so poorly with the PEG feed, I reached out to Helen for her expertise often. I was desperate for help. My Mum was deteriorating rapidly. It wasn't always easy to get to speak to Helen and I'd leave a message for her, the care agency we used Caremark also stepped in to help me with the communication. Sometimes while I waited for Helen to get back in touch with me, I had no idea what was going on. I didn't know what she was doing in the background. And then I'd talk with her, and she would tell me that she'd been in touch with a plethora of people, consultants, advisors, my Mum's GP and anyone else who may help. She was very invested in helping Betty. She worked so hard and seemed to always be looking for a way to cast her net wider to find a solution."**

Betty experienced sickness and diarrhoea and gastroenteritis, complicated by also catching Covid19 and having a digestive system that preferred soya to lactose. **"Helen asked us to keep a chart of when Mum was sick or had diarrhoea. Helen tried everything – flushing the tube out, changing the time of feeds, changing the speed of feeds. The carers had to keep up with the changes that Helen recommended. They were amazing!"** Kay continues, **"We knew the end was coming but we weren't giving up! Helen was so invested and dedicated to my Mum's care. I'd sent her an email at 4am on the morning she was due to return to work from holiday, hoping it would be at the top of her inbox when she checked her emails. The same day, as soon as Helen had done the school run, she came straight round to see Mum to see what she could do for her."**

"We had some extremely frank discussions about the state of Mum's health. Her GP was always very straight with me, we knew Mum was dying but we never, ever stopped working as a team, to get her the right nutrition and try and give her a bit longer to be with us all. In the end we only gave in when she did. Helen's dedication was incredible, she was the ultimate professional. She stepped up even further to help Mum because she could see the woman she was. She even came to Mum's funeral. She epitomises the dedication that everyone in the NHS eventually gave my Mum. Her knowledge was incredible. She was the last health professional involved in Mum's care and it was an honour to work with her."

Kay says Betty's passing was peaceful. **"The end-of-life treatment she received was given with an empathetic and compassionate approach. Although she slept through the many visitors she had, we all got the chance to say goodbye to her. I didn't leave her side, they allowed me to stay with her the entire time (48 hours). She only woke twice, once when Dad cried out in anguish and the next, just a few hours before she died, she opened her eyes and looked straight at me, I went to her, she pursed her lips and gave me a kiss, she kissed me 3 times, one for each of us. She closed her eyes immediately after and never woke up again. We have been so afraid to lose her, our biggest fear was her dying but when she did, she did it in a beautiful and elegant way, she drifted into death. Almost like a swallow dive. She did it comfortably and confidently. She taught me the most valuable lesson of all, not to be afraid of death."**

Kay reflects on her role as carer and advocate, **"It's important to be confident when dealing with medical professionals, to work with them, to be curious, and not be afraid to speak up. If people use jargon, ask what they mean! Don't be afraid to ask questions and look for solutions. Be invested in your own health care."**