

# And The Beat Goes On

Sitting alone in the sterile hospital room she tried to remember what it was like to be well. Sometimes her mood would turn solemn as she thought about how much her world had changed in the previous nine months.

When she first started to feel exhausted and her breathing began to labour she had no idea her life was swaying in the balance.

Sandra had gone to her doctor because she thought she had a chest infection. She was told she had pneumonia and was sent home with antibiotics. She was hoping the medication would make her feel better but as the days dragged by her health continued to deteriorate.

Her breathing became more difficult and then she noticed a large hard mass forming at the base of her rib cage. It didn't take long for the mass to get so large it could be seen through her clothes and it was becoming uncomfortable for her to sit.

As she was finishing off the course of antibiotics her doctor went on holidays. She wasn't getting any better so she went to see another physician. It was then she discovered there was something wrong with her heart.

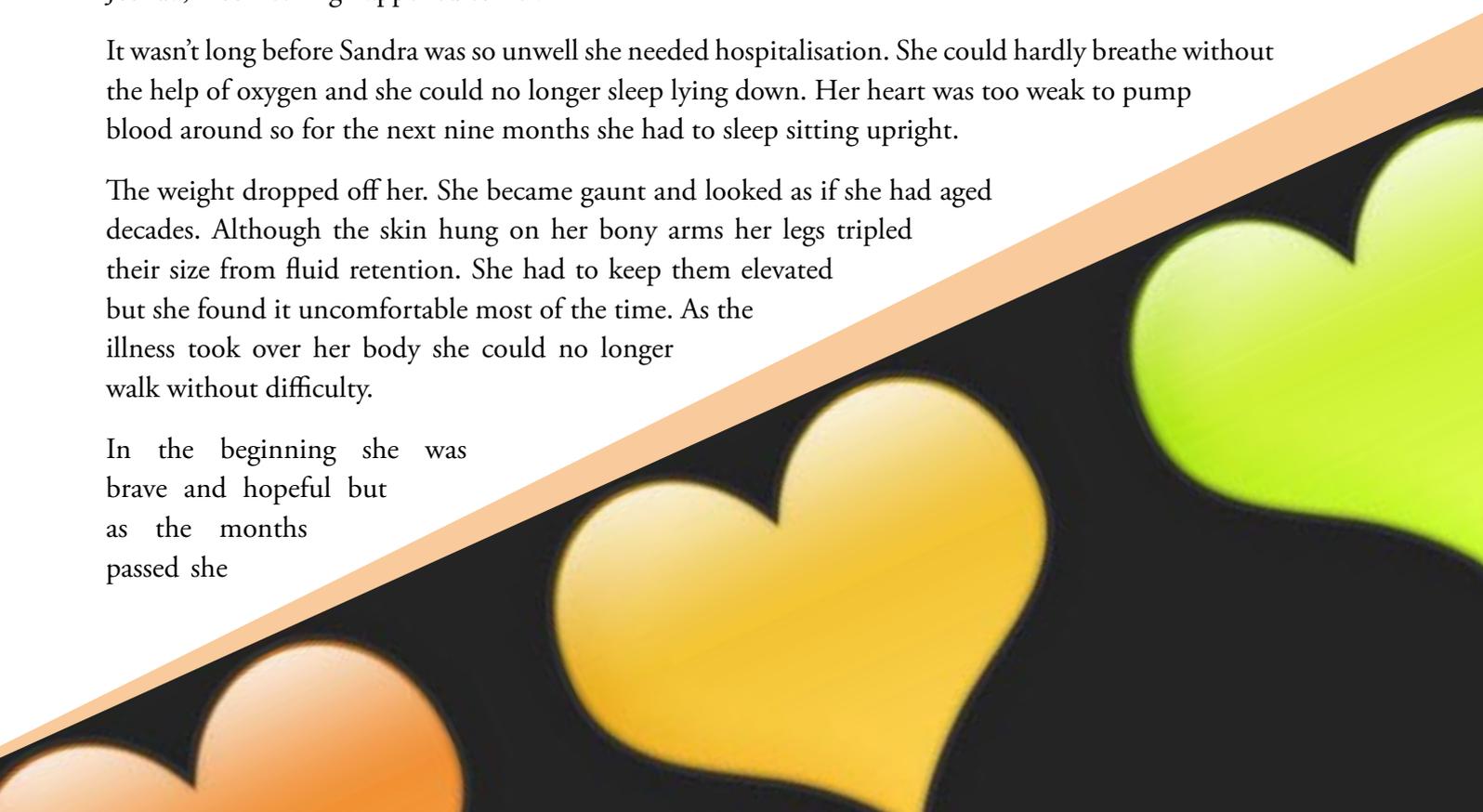
When she told one of her close friends she had 'cardio myopathy' they thought about the movie 'Beaches', where Bette Midler and Barbara Hershey played best friends in an emotional movie about friendship and dying.

Her friend remembered how Barbara's character lost her fight with the same illness and that after her death her daughter had to be taken care of by her best friend. Sandra wondered who would look after her 13 year old son, Joshua, if something happened to her.

It wasn't long before Sandra was so unwell she needed hospitalisation. She could hardly breathe without the help of oxygen and she could no longer sleep lying down. Her heart was too weak to pump blood around so for the next nine months she had to sleep sitting upright.

The weight dropped off her. She became gaunt and looked as if she had aged decades. Although the skin hung on her bony arms her legs tripled their size from fluid retention. She had to keep them elevated but she found it uncomfortable most of the time. As the illness took over her body she could no longer walk without difficulty.

In the beginning she was brave and hopeful but as the months passed she



became weary. She hung to her faith like a child clings to their parents the first time they're being left somewhere unfamiliar. She tried to find reason why God would make her suffer like this and she prayed not to lose faith that she would be saved.

It was hard for her friends to see her this way. She had turned into a frail sickly person who had little quality of life.

Some of her friends were not able to see her without getting emotional. She would comfort them but she never cried for herself.

Instead she cried for her son, who had gone to live in foster care. He was different now – this illness had changed him. Suffering from Neurofibromatosis and displaying oppositional type behaviour, which made living with him a challenge, he was always energetic and childlike, but that was before she was diagnosed.

In his first foster home he wasn't happy but he wouldn't say why. He was moved to another family and seemed more content there. Sandra felt guilty that she couldn't be with him.

Even though hospital was the best place for her, she hated being there. She wanted her life back and wanted to go home.

She was sent to Sydney to be assessed for a heart transplant because the cardiac team at the Canberra Hospital knew she would not survive without one.

She stayed at St Vincent's Hospital for months. Her ward was full of people waiting for transplants and others who had suffered heart attacks. The specialists worked very hard to keep her alive until a heart became available.

Not long after she got to Sydney they operated to replace a heart valve. After the operation she died twice and the beat stopped ... but they brought her back.

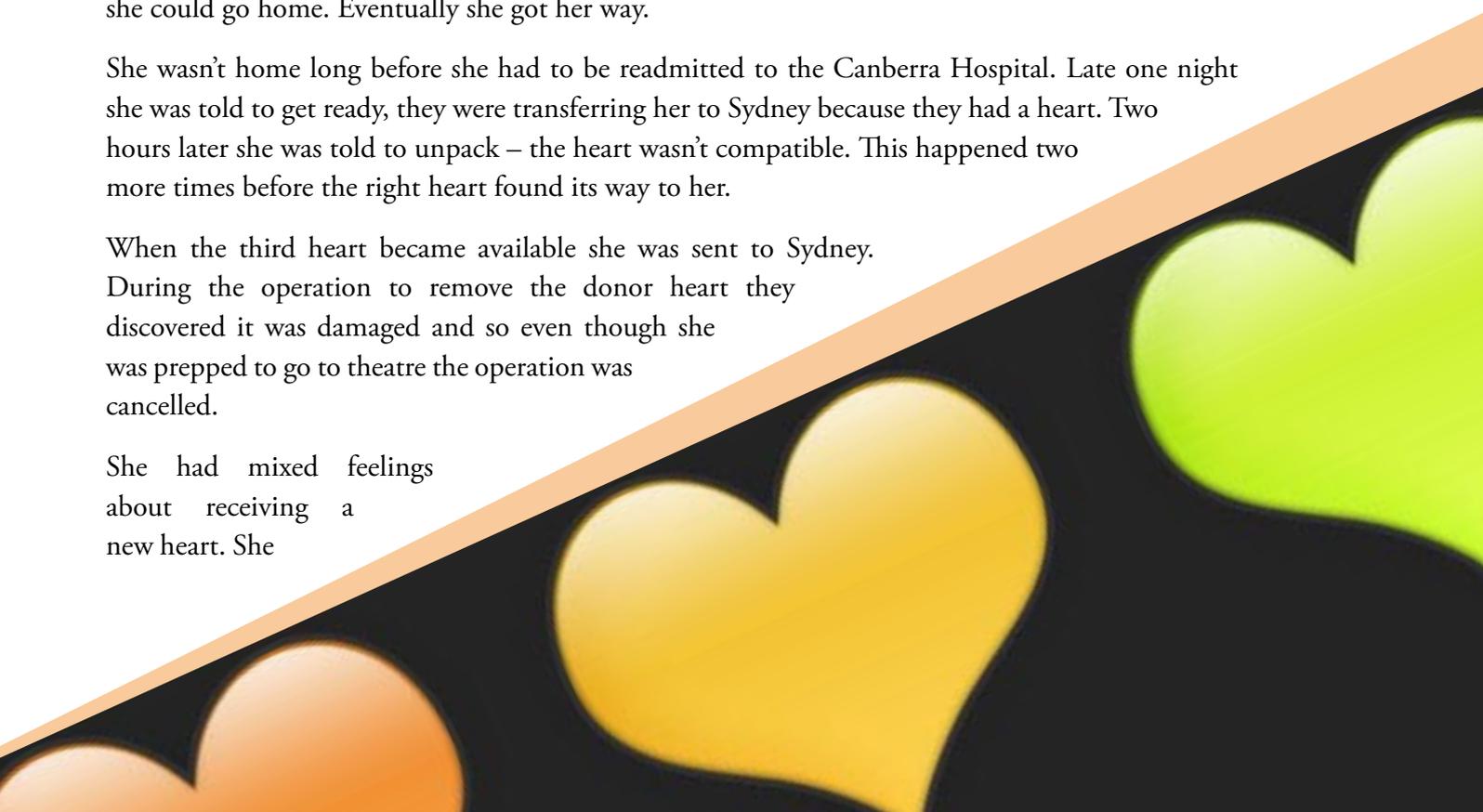
A few weeks later, as a team of trainee specialists came to visit her ward, she suddenly felt very dizzy. She called out trying to let someone know. When she woke up in ICU later that day she found out that she had died for four minutes. Again they were able to revive her. Although she didn't remember anything she became very frightened about her future.

After that they gave her a fibrillator. She felt safer with the device inside her and so she kept asking them when she could go home. Eventually she got her way.

She wasn't home long before she had to be readmitted to the Canberra Hospital. Late one night she was told to get ready, they were transferring her to Sydney because they had a heart. Two hours later she was told to unpack – the heart wasn't compatible. This happened two more times before the right heart found its way to her.

When the third heart became available she was sent to Sydney. During the operation to remove the donor heart they discovered it was damaged and so even though she was prepped to go to theatre the operation was cancelled.

She had mixed feelings about receiving a new heart. She



thought she wouldn't make it out of the surgery so she prayed for a miracle instead – she wanted her own heart to get well.

Leading up to the transplant they did everything they could to get her well enough to survive the operation. She was taking around 30 tablets a day to keep the heart pumping and reduce the severe fluid retention problem.

The day finally arrived.

Late one night she was told they had a compatible heart. A team of doctors at St Vincent's Hospital worked for six hours to remove her dying heart and replace it with one they hoped would bring her new life.

Within days of the transplant she was a different person. Although she felt better she was terrified to lie down to sleep - she was worried her heart would stop beating. The nursing staff carefully convinced her that everything would be alright and it was.

She is now home after being monitored closely in Sydney for three months. She is thrilled to be alive but doesn't really like her new face, which has changed shape from all the medication she takes. She also misses her size 10 waistline which has rounded and thickened from the steroids which she takes so her body won't reject her new heart.

Her son is still not living with her full time but they are enjoying getting used to each other again. She needs to get a job because her bills have piled up during her illness but she is worried she will have difficulty convincing a business she would make a great employee.

Everyday she thanks God for saving her and when she thinks about how sick she was she's glad the feelings of despair and fear over the last twelve months are now being replaced with optimism about the future. She even found herself laughing the other day which had her wondering about the last time she laughed – it seemed so long ago she couldn't even remember.

The beat may be different now but it still goes on.

