

Alan's story

Alan and I worked together in the printing trade for 10 years, starting in 1987. Then we suddenly realised that we were meant to be together. The first time he kissed me it was like something out of the movies! We got together and had our daughter Holly fairly soon in 1997. We lived in a flat in Worthing and later we had our son, Max. He's 13 now. We had a really happy family life. Alan liked a joke. He used to do silly things like put pants on his head! He loved his garden and spent a lot of time out there.

It was a couple of years ago, in 2017, when things started to go wrong. He was finding it increasingly difficult to walk without feeling tired and breathless. He went to the doctors a few times. He was 70 at the time so they just put it down to just his age. But things got so bad I told him to go back. So he went and they sent him for an x-ray at the hospital.

I got a call at work from Alan at the hospital. He was in tears because they'd said to him, 'You can't go home. We need to keep you in and get your wife to come in.' Initially, I just thought it was pneumonia or something like that. So we waited in A&E for a while, and then they called us through and just said 'It's cancer.' They'd seen it in his lungs. He was sent for a CT scan and they found it not just in his lungs but also in his kidney, spine and lymph. He'd always been so active and healthy. It was such a shock. We really struggled to take it all in. I remember we kept going into the garden to cry. It was all so surreal.

It was really important to me and Alan that we dealt with telling Max about it in the best way we could. That was when we first tapped into the help available from St Barnabas - when we got advice



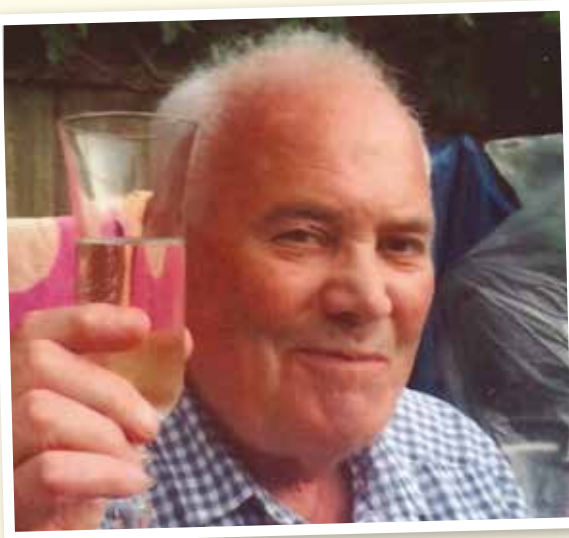
from the Bereavement Team on the best way to deliver the news. One of the Social Workers at St Barnabas, came to see us. She gave us some books to use. It gave us an opportunity to open up conversations with Max. We did really need the help because when you're dealing with a child, you don't quite know what their mind is thinking and you don't want to suggest things that they might not have been thinking. So we would work through the pages of these books and it would just prompt him to talk about how he was feeling.

When we told Max, his initial reaction was, "Will he die?" but of course, we didn't know. So we said "There's a possibility but the doctors are going to give him medicine. We might have more time together - we just don't know." He said, "If I could have him for another year, that would be okay." In the end, Max actually his got his wish.

Anyway, the next thing that happened was I insisted Alan had a brain scan because I just had this feeling: it's everywhere so what is the chance that it's not in his brain too? So they scanned his brain and, yes, he had it in his brain as well.

He had five days of radiation therapy on his spine and brain. And then, after that, he got put on to chemotherapy tablets. The doctors felt there was too much chance of infection for them to use intravenous drugs. He didn't have too many side effects but he did develop cellulitis in his legs. Actually, that was the most debilitating thing. It was horrendous. It got to the point where it was down to his bone. It just got worse and worse. He became chair-bound in the early part of last year. He was really frustrated and missed his garden so much.





Around this time, Alan visited the Day Hospice at St Barnabas a few times. He did some art there, which he really enjoyed. Alan also received support from Mike, one of the hospice's Community Companion volunteers. He found his time spent with Mike extremely beneficial. At the same time, it gave me a break and meant I could do things such as going shopping.

There was something else that St Barnabas facilitated, which was fantastic. Alan and I had a special place – a local beauty spot where we used to walk a lot in our early days. It was a beautiful, magical place where we spent so many nice times. In fact, it was where he asked me to marry him. I thought we'd never get to go there again. Lucy, the Occupational Therapist, from St Barnabas came to visit us and we just happened to mention it. Then, the next thing we knew, she arranged to have a motorised scooter brought up so we could go there. It was really special.

By this time, Lucy and the Hospice at Home Team from St Barnabas were visiting us here at home because Alan didn't want to go into the hospice. It had got to the point where, because he was bed-bound, he needed a lot of care. The Hospice at Home Team were just so special. They never rushed. They used to do everything. The nurses were so lovely. They would remember silly little details that you wouldn't even think of. It's such a personal touch they provide. And it wasn't just Alan they were looking after – it was all of us.

Alan went away for a month of respite care with another care provider but he got a chest infection while he was there. Once it had cleared up, he was desperate to come home – and he came back on Tuesday 12 June last year. One of the Community Nurses, came to see him and she said she could get him into St Barnabas on Sunday – but on Saturday you could see that he'd changed. You could see that his behaviour had changed. He was kind of not really there and grasping at things and quite agitated. On Saturday morning he said to me, "goodbye my love."

On Sunday, the ambulance came and took him to St Barnabas. I'm so glad he went there. The facilities there are amazing and all our family and friends came to visit. The nurses are so expert at dealing with it, they were able to manage it. At about 9 o'clock in the evening, everyone had gone home, it was just Max, Holly and I. Alan had really laboured breathing – he'd sounded like a drain – for a couple of days. Then Max realised something had changed. The breathing sound had gone. He was breathing normally. I sat next to him and said "I'm here." Then he took one last breath and just slipped away.

Since then, we've all continued to receive amazing support from St Barnabas. Holly and Max have both had bereavement counselling, and I still see the Social Worker, Elaine, around once a month. We would never have got through this year as well as we have without that support. The Bereavement Team at St Barnabas have seen this so many times so they have a wealth of knowledge to pass over to you. But you also feel that you're really heard. They have brilliant ways of dissecting what you've said and they'll come up with this fantastic one liner that sums it all up and makes you feel better about everything. It's incredible. Some days it's more difficult than others but there's a sense of warmth and love there. You come out feeling like you can take on the world a bit more than you did when you went in.

We also got so much out of the Light Up a Life service last December. Our first Christmas without Alan was tough. But going to the service was a really lovely place to focus on our sadness, surrounded by people who felt exactly the same or similar to us. Just to have an hour or two to allow the sadness to come and have a cry, and to be around people that you don't even have to say anything to – they just know. That is special. Even in such an awful time, we met some amazing people and the experience of the service was incredible.

We are all of us going forward with a sense of optimism and positivity because of the help that we have had from St Barnabas. There's no way that we'd be in this position now, without that help. We would not be moving on with our lives as well as we are.

If you can, I urge you to make a gift to St Barnabas so they can provide the same amazing care for even more local families who will need it in the months ahead. I promise, your generosity will make a huge difference to so many people's lives exactly when they need it most.

With warmest thanks and best wishes,

Nina