

*A CELEBRATION OF THE LIFE
of
Robert John Soper*

15th June 1956 – 27th July 2018

Foal Wood, Kent
11am, Tuesday 28th August 2018

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The Tribute

All of you here today knew and loved Robert. I had the honour to meet him, only once, when he asked me to come and talk to him about what kind of funeral he wanted, and to tell me stories of his life and his enthusiasms. It was a real privilege to meet him. He was clearly someone who, despite the difficulties which life had thrown at him, had a passion for living and a real interest in the world around him.

He was born on June 15th 1956, the middle child of Joyce and John Soper. Joyce recalls Robert as being a very easy child. Looking back at Robert as a baby Joyce remembers he used to cry whilst the pram was being pushed along but would immediately stop when it stopped – the first indication that he had a balance problem. Gradually Joyce and John noticed that Robert was showing more signs of problems with his co-ordination and balance.

By the time he was 5, they discovered Robert's eye sight was very bad. And at the age of 8, in 1963, Robert attended the North Middlesex Hospital for physiotherapy for cerebral palsy.

It wasn't until Robert was in his 20's that Guys Hospital diagnosed that he had Ataxia-telangiectasia, a complex condition, which affects people in different ways. Gradually co-ordination and movement are affected, and these co-ordination problems start to effect speech, and also, over time, eating and swallowing. There was no effective treatment or therapy available at that time, and apparently there still isn't.

Despite this, he remained engaged with the world around him, and never complained, or said that his suffering was unfair.

The family were then living in Hemel Hempstead. Robert started at the local primary school, Bennetts End, and at the age of seven he moved on to Hobbs Hill School. Robert experienced some bullying while at these schools, but that soon stopped once his big brother stepped in! He then moved on to be a weekly boarder at Thomas Delarue school in Tonbridge, where he was very

happy. He told me that, while he'd never consider himself to be academic, he was popular, made lots of friends, and the life there suited him. The school's motto was "There is no failure other than ceasing to try", a sentiment which stayed with Robert all his life.

After he left school in 1973, he returned to live at home. In 1976 the family moved to Paddock Wood and stayed there till 1995. Robert felt well supported, particularly by Joyce: "She was a good Mum to live with" he told me. But eventually he moved out to a flat in Ringden Avenue, and then to Coxheath in 2005.

For someone with such a debilitating and progressive condition, Robert managed to live an amazingly active life. He loved his travels – family holidays around the UK, a camping holiday to Brittany, and trips to Cyprus and Normandy with his parents - school trips to the Isles of Scilly and to Holland - and organised trips to Malaysia, Singapore, Egypt, South Africa and Israel.

He used to go bowling at the Angel Centre in Tonbridge where he became well known - not only for his enthusiasm and sheer determination but also for his sense of humour, especially on the days when the bowls didn't end up where he wanted them too! He was a valued member of the bowling club.

He was particularly fond of sailing and sailed regularly on Bewl Water with his mother and father, and also with a voluntary group. In recent years his carer took him out on Bewl Water several times, and these trips gave Robert much enjoyment. But most exciting of all were his adventures as a member of the crew on the Jubilee Sailing Trust's flagship, The Lord Nelson. Robert attended the launch and naming ceremony which he remembered as a great honour.

Because of this passion, and at his request, I will now read John Masefield's great poem for all who go down to the sea, Sea Fever:

*I must go down to the seas again, to the lonely sea and the sky,
And all I ask is a tall ship and a star to steer her by,
And the wheel's kick and the wind's song and the white sail's shaking,
And a grey mist on the sea's face, and a grey dawn breaking.*

*I must go down to the seas again, for the call of the running tide
Is a wild call and a clear call that may not be denied;
And all I ask is a windy day with the white clouds flying,
And the flung spray and the blown spume, and the sea-gulls crying.*

*I must go down to the seas again, to the vagrant gypsy life,
To the gull's way and the whale's way where the wind's like a whetted
knife;
And all I ask is a merry yarn from a laughing fellow-rover
And quiet sleep and a sweet dream when the long trick's over.*

He had a great sense of humour, a mischievous smile and a great chuckle. Many years ago, Joyce, John and Robert went to dinner at Patricia's. She'd made a casserole, and as she took it out of the oven, she put it down on a cold surface, and it exploded. The last time she and Robert spoke, shortly before his death, she suggested that she'd come over and they could go to the pub together for something to eat. Robert said that he'd like that and said with a chuckle "you know you're safe with a casserole there".

Whilst living in Coxheath, Robert had many carers over the years and there were a few that he grew very fond of. With them, he went regularly to the Hop Farm (which boasted excellent disabled access, and where Robert was well known), and weekly visits to the 'Club' in Tonbridge as Robert fondly called it, where he made many friends. A highlight for Robert, which he mentioned to me, was a trip to Down House, home of his hero Darwin.

The thing about Robert was that he loved to talk to people, to hear about their lives and discuss things with them, so almost everyone who came into his home was welcome for bringing a new perspective.

As he became less mobile, he became increasingly reliant on his computer, which acted as one of his windows on the world, though it was a very slow process for him to type, using his “Grid” keyboard. Eventually, he found this to be almost impossible. He loved films, particularly nature documentaries, and was a great fan of David Attenborough. He loved all sports, particularly football, and most of all Liverpool – he said the club had had its golden years when he was growing up, and he was clearly delighted that they were once again doing well under Jurgen Klopp. And he loved music – he had a huge collection, and very eclectic tastes.

Most people with AT have a reduced life expectancy. At 62, Robert was almost certainly the longest-lived with the condition in the world, and he was very amused to find that a woman from East Grand Forks Minnesota was claiming to be the oldest survivor at the tender age of 39. He was going to write to her to put her right but decided there was no good reason to take her pleasure in her achievement away.

On July 26th, after Robert had watched his club Liverpool win 2-1 against Manchester City, Carl, his carer, supported him to get to bed as usual. Robert had a routine for this, and once he had left the bathroom and headed for the bedroom, he never spoke to his carers, but on that evening when he reached the bedroom, he looked at the pictures there of all his travels, said “Those were really happy times”, and smiled.

We often think of death as a cruel enemy, taking away those we love, but for those who are suffering or who have reached the end of their endurance, it can come as a quiet friend, settling us into a last sleep, free from pain and weariness.

And I hope it was so for Robert.

