ANNA’S LEGACY

Just over 20 years ago my little sister Anna died from a rare form of cancer at the age of 31. It was a cruel illness, one that forced her in and out of hospital many times over the five years that she fought the disease.

However, Anna was never one to dwell too long on the downside of any situation; instead she was always looking for the next excuse for a laugh and a party. Cancer was no exception; ‘I’m not going to let this thing get the better of me’ was her attitude. In that time she often bolstered her determination by embarking on a series of specially planned days and nights out that would counterbalance the misery of chemo, radiotherapy and many operations.

To see her dressed up glam, laughing uproariously out of the window of a stretch limo, toasting everyone she passed as we cruised through the West End, was enough to help forget she had cancer. A special day wasn’t just about blocking out the ever present, it was about turbo-boosting her confidence and looking to the future with hope and excitement.

It was this attitude which led my mum and dad, Bob and Megs, to seek ways to channel Anna’s positivity at a time of such huge loss. The result, of course, was an amazing charity whose core mission not only borrowed Anna’s nickname but also her inspirational approach to life, and death. I am delighted to have been appointed as a Trustee at a time when we can proudly mark the achievement of having delivered, since the launch of Willow in 1999, more than 16,000 Special Days to young people who need positive relief in times of pain and anxiety. As Anna would be the first to remind us, that’s well worth celebrating!

John Wilson
Anna’s brother and Trustee

20 YEARS OF SPECIAL DAYS AND TREASURED MEMORIES

DAVID’S SPECIAL DAY ALLOWED HIM TO FULFIL A FINAL, LIFELONG DREAM

When David, 27, was diagnosed with terminal bowel cancer, he applied to Willow to help him realise his dream to go to Wimbledon. David fulfilled his wish, just three days before he passed away. The memories of David’s Special Day in 2012 still hold such fond memories for all the family. Here, his mum Susan shares his story:

“When the day came for David to fulfil his dream of going to Wimbledon he was unfortunately extremely poorly, but everyone rallied around and made sure he was as comfortable as possible for his Special Day. David watched the matches from the disabled area which meant I was able to see him lots on the television. Watching David and his brother John laughing together and enjoying themselves is a memory that will stay with me forever.”

March 2019
16,000th Special Day provided

From 17 Special Days in year 1 to 1,199 during 2018

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THE SERIOUSLY ILL YOUNG ADULTS WE SUPPORTED IN 2018

Every day we estimate that more than 40 young adults, aged 16 - 40, receive a diagnosis of a serious or life-threatening illness, people who could be eligible for a Special Day:

NUMBER OF SPECIAL DAYS CREATED 1,199

BY CONDITION
- Cancer: 1105
- Cystic Fibrosis: 21
- Organ failure: 12
- Muscular Dystrophy: 8
- Huntington’s Disease: 4
- Other degenerative/genetic conditions*: 49

*including motor neurone disease, ataxia telangiectasia and other rarer conditions

BY AGE
- 16 - 20: 10%
- 21 - 30: 35%
- 31 - 40: 55%

In 2018, 92% of our Special Day beneficiaries were living with cancer

BY LOCATION
- East: 9%
- East Midlands: 8%
- London: 6%
- North East: 4%
- North West: 17%
- Northern Ireland: 3%
- Scotland: 6%
- South East: 14%
- South West: 11%
- Wales: 5%
- West Midlands: 8%
- Yorks & Humber: 10%

BY GENDER
- Female: 71%
- Male: 29%

Willow will always support more young women compared to men because women are twice as likely to receive a cancer diagnosis in the age range 25 - 40.

SPECIAL DAY ELIGIBILITY CRITERIA

Willow provides Special Days for seriously ill young adults. To be eligible, the applicant must be:
- Aged between 16 and 40
- Resident in the UK
- Receiving treatment for a life-threatening illness or life-limiting condition, including cancer, motor neurone disease, cystic fibrosis, Huntington’s disease and many other conditions.

WORKING WITH THE MEDICAL PROFESSION

Willow’s two part-time Nurse Advisors raise awareness of our Special Day service with their peers. This has resulted in 147 new referrers in 2018, including GPs, consultants, social workers and nurses such as Fiona:

“As a clinical nurse specialist working with 16-24 year olds with cancer, Willow’s support and provision of Special Days is something that we try to ensure most of our patients apply for. When patients are going through many months of treatment for their cancer, the opportunity to have a Special Day is always something they look forward to. The opportunity allows them to bond with loved ones again after a very stressful time as well as do something that is ‘normal’ again, away from hospital visits.”

Fiona, Clinical Nurse Specialist, Edinburgh Cancer Centre

• 850 medical professionals referred 1,631 patients to Willow for a Special Day in 2018.
• 165 medical professionals referred multiple patients to Willow during the year.
• Our nurses performed 1,689 medical checks and updates and advise our Special Day Makers on any medical requirements when organising and booking Special Days.
LIVING WITH A SERIOUS ILLNESS

Being diagnosed with a life-threatening illness has a profound affect on people. Alongside the many hospital appointments and often long treatment plans, research* shows that young cancer patients experience anxiety and isolation, often coupled with a less obvious burden of the financial impact of their diagnosis.

Our Special Days support seriously ill young adults in the here and now, when they are faced with the emotional and practical impact of their illness. In 2018, 92% of our beneficiaries were living with a cancer diagnosis and each would have experienced anxiety, isolation and financial worries in varying degrees.

ANXIETY

When patients start treatment, there is never any guarantee that it will work, creating very real uncertainty about their future. Ninety percent of young people experience anxiety during their cancer treatment.

Our Special Days provide families with the opportunity to spend time away from the difficult realities they face every day.

“Receiving the news the week before my Special Day that my cancer had spread was devastating, but the prospect of having a few days away lifted my spirits when I needed it the most. Living with a serious illness is stressful and worrying, but my Special Day allowed me to forget about my illness, even for just a few days.”

ISOLATION

A cancer diagnosis is relatively rare for the age group we work with. Less than 1 in 10 new cancer cases affect 16 to 40 year olds and less than 1 in 100 new cancer diagnoses affect teenagers. Many beneficiaries will also have had to interrupt their education or give up work for many months because they are too unwell and treatments prevent them from continuing life as normal. As a result, the cancer journey at this age is devastatingly lonely and research* suggests that 83% of young people experienced loneliness during their cancer treatment.

At this point a Special Day makes young people feel part of life as they knew it and injects some normality back into their lives.

“Since diagnosis, I distanced myself from everyone – I didn’t really talk to anyone, I shut myself in my room and felt like giving up, despite everyone encouraging me to stay strong.”

FINANCIAL IMPACT

Cancer is often described as the toughest fight most people will face, but cancer is also expensive. Four in five people with cancer are on average £570 a month worse off because of their diagnosis, while many are also faced with reduced income. This double hit results in financial worry at anxious and uncertain times.

Our ability to organise and fund what are often, on the surface, modest requests, makes a huge difference to the lives of seriously ill young people.

“We were a loving, happy family with the world at our feet. Cancer has shattered everything. In less than a year Lorna’s cancer has spread. I have left my job to be a full time carer and house husband. The kids were so excited about the Special Day. I’ve never heard “can we go again” so many times in my life! You gave us priceless family time, new photographs and special, irreplaceable memories.”

MACMILLAN PARTNERSHIP

Macmillan enables Willow to reach out to young people whose cancer diagnosis and long-term treatment has resulted in financial hardship for them and their families. We understand how financial difficulties place a huge amount of pressure on patients and their families, at a time when they are already having to balance their normal life with the demands of treatment. Since the partnership started in mid 2016, we have created more than 200 Special Days for seriously ill young adults who were introduced to us by Macmillan.

*Macmillan, Willow, CRUK and CLIC Sargent
Now in our 20th year, our strategic goals focus on the following key areas:

**GROWTH**
- We will continue to build and diversify Willow’s fundraising income with a focus on long-term sustainability and regular giving.
- In order to grow our supporter base and beneficiary reach, we will continue to raise awareness of our service and organisation nationally.

**IMPACT**
- We are committed to deliver more than 1,000 high quality and individual Special Days for seriously ill young adults and their families per annum.
- To introduce quantitative based service impact reporting to complement our qualitative efforts already in place. Clear impact and outcomes will allow us to provide better reporting to our funders and will inform our communications.

**SUSTAINABILITY**
- We aim for our organisation to operate with financial sustainability whilst maximising its resources in an efficient and cost effective way.
- We are focusing our efforts on building strategic and long-term partnerships. In addition, we understand the importance of diversifying and growing our networks to extend our reach.

**THE IMPACT OF SPECIAL DAYS**

In November 2018 we contacted beneficiaries who experienced their Special day between 2010 and 2014 and asked them how they feel about their day now.

More than 90% agreed that:
- their Special Day still brings joy to them and their loved ones.
- they continue to have positive memories of their Special Day.

When asked “How do you feel about your Special Day today?” these were some of the powerful messages that we received:

- “I spent it with people close to me, doing something I was scared to do and everyone at the RAF was so good. I’ll never forget it!”
- “This was the last time we went away together, my wife has now passed away.”
- “It created lots of happy memories for our two young daughters at a very hard and worrying time of our lives. We still think back to our trip with happy memories.”

**“CAMERON’S SPECIAL DAY GAVE US ALL THE BOOST WE NEEDED.”**

Cameron, 18, is living with Duchenne muscular dystrophy. He is cared for at home by his family, where his mum, Lisa is his primary carer. Here she shares Cameron’s story:

“Cameron’s diagnosis of Duchenne’s muscular dystrophy saw all our future plans come to a halt, the family we dreamed of was turned upside down and our lives changed forever.

We knew that as Cameron got older there would be things that he wouldn’t be able to do. As a family, we tried to cram everything that we had dreamed of doing into just a few years, instead of over a lifetime.

As time goes by there is less and less that he can do, his condition is deteriorating rapidly and eventually he will be totally bed bound. As heartbreaking as that reality is, we have to do as much as we can while he is able to and this is our priority.

When Cameron heard about his Special Day he was so excited, it gave us all such a huge boost, something that we could all look forward to and focus on.

Cameron’s Special Day to Whipsnade Zoo created many magical memories for us all, it gave us amazing quality family time together. But the one memory that we will treasure the most is when Cameron saw a wolverine, it is something he has always wanted to see and that really made his day.”