The past year has been a challenging yet rewarding year at Willow. It was a period of rebuilding our fundraising and service capacity while working with health professionals to prioritise those beneficiaries in greatest need.

Giving quality time to seriously ill young adults aged 16 to 40, has been our sole purpose since our foundation in 1999. Throughout 2022, we have focused on growing our reach to young adults living with incurable or life-limiting conditions other than cancer and those living with rare diseases. In reality this means that we are giving priority to 16 to 40-year-olds who have limited time or who are living with complex needs.

We have experienced a significant upturn in demand for our services since Covid-19 restrictions ended. With a clear focus on priority groups, and efficient allocation of resources, we have risen to the challenge. Thanks to your generosity we were able to help 1,158 seriously ill young adults make precious memories during 2022.

We are proud of our partnership with the Alexion Charitable Foundation, who approved a significant grant to fund Special Day services for young adults living with rare conditions, as well as rare cancers.

On the fundraising side, all our planned campaigns and events took place without interruption. Five years ago this would have been a surprising comment to make, but after the huge upheaval that the charity sector has felt during the pandemic, we are grateful for a full year of fundraising activity.

Thank you to all supporters who have stood by Willow and who went the extra mile to support us.

Jonathan Aves
Chief Executive Officer

Lorna, 36, from Chichester is receiving treatment for cervical cancer. She chose to spend her Special Break at Blackwood Forest, which was the first holiday for Lorna, Dan and Joshi.

“Our Special Break was just incredible. I honestly don’t have the right words to express how grateful we are. It was exactly what we needed and gave us a complete break from normal life. We were able to spend time as just a three (plus the dog) and genuinely forgot about everything that is going on for four days of complete bliss.

When I was re-diagnosed in April 2022 our whole world shattered. We had a six-month-old baby who we had welcomed the previous September via surrogacy and never expected my cancer to return. I am in active treatment and so far scans have been very encouraging but I have treatment every three weeks which has completely taken over our life.

We have an amazing team around us, and we do our best to keep up a sense of normality, but cancer creeps into every part.

The weekend reminded us that there is life around cancer and it has given us the confidence to think about trying to have more experiences as a family that make lasting memories. It also gave us the rest we needed between treatments for my body to recover. The hot tub was an excellent place for a sore body too.”

Lorna’s Special Break

Our impact

88% said the Special Day gave them much-needed quality time with loved ones

67% said the prospect of their Special Day offered much-needed distraction from treatment and hospital appointment

74% told us that they could not have afforded the experience themselves

87% said our service gave precious memories that will last forever
2022 overview

Beneficiary focus in 2022

Our service focus is directed at seriously ill young adults in greatest need. This is defined by our medical advisors with feedback from referring medical professionals and organisations across the UK. Our priority patient groups include those living with:—

• **incurable conditions**, where sadly there is a short period to create lasting memories with loved ones.

• **life-limiting conditions** (i.e. degenerative, genetic and metabolic), often with very complex day-to-day needs and with a significant impact on quality of life.

• **rare conditions**, journeys that are often lonely and isolating, with very little support available compared to more well-known conditions with larger patient groups.

An overwhelming 75% of our beneficiaries fall within one or more of the above three categories.

Raising awareness within the medical profession

To reach our priority patient groups, Willow’s medical advisors have expanded networks that refer patients to Willow. In 2022 our medical advisors attended the Palliative Care Congress in Telford and the NHS Oncology Conference in Manchester. They regularly participate in virtual meetings with healthcare groups and patient support organisations such as Rett UK or Huntington’s Disease Association. Building these relationships is crucial and we are enormously grateful to the healthcare professionals up and down the country who value our work and continue to refer their patients to Willow.

Services for all

Willow offers a range of four different services: **Special Breaks, Special Days Out, Special Days at Home** and **Special Treats**. This gives beneficiaries choice, but importantly enables us to support young people who are too poorly, have complex needs or feel unable to participate in an activity away from home.

In 2022, Special Treats became a permanent part of our service. Treats are delivered through our ‘Gift to You’ programme and focus on young adults who are receiving end of life care or 16 to 25 year olds living with degenerative and genetic conditions who are transitioning between the support of a children’s hospice and an adult hospice.

We reached these young adults through partners such as Hospice UK, Together for Short Lives, Children’s Hospices Across Scotland and other palliative care settings across the UK.

We continue to develop our treat service and new items tailored to the needs and individual situation of beneficiaries are introduced regularly. For example, a range of sensory items especially for those with complex needs was added as well as a ‘Name a Star’ gift box to give families a lasting memory.

James’ Special Treat

James is 21 and lives with Angelman Syndrome. For his treat, Willow tailored the contents to James’ complex needs and we included a variety of tactile and sensory items designed to engage and stimulate his senses.

“The box arrived beautifully packaged and James was encouraged to open it when he returned from his day care service. It arrived on February 15th which is International Angelman Day, a day that raises awareness of Angelman Syndrome and celebrates those with the condition, thank you for recognising this day and the patients.

James was really happy to explore the contents and it will provide entertainment and pleasure for a long time to come.”
Who we have supported in 2022

**Gender split**
- 63% Identify as female
- 36% Identify as male
- 1% Identify as non-binary

Women account for double the incidence of cancer in the age range 25 to 40 compared to males, which is reflected in our support numbers.

**Age**

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>16-20</td>
<td>17%</td>
</tr>
<tr>
<td>21-30</td>
<td>37%</td>
</tr>
<tr>
<td>31-40</td>
<td>46%</td>
</tr>
</tbody>
</table>

We supported young adults with 43 different types of cancer.

The three most common cancers supported were breast cancer, lymphoma and leukaemia and they represented 47% of all cancer support.

The rarest three cancers supported were bladder cancer, cancer of the salivary gland and throat cancer. They made up just 0.5% of all cancer support.

**By location**

<table>
<thead>
<tr>
<th>Region</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>East</td>
<td>14%</td>
</tr>
<tr>
<td>East Midlands</td>
<td>7%</td>
</tr>
<tr>
<td>London</td>
<td>7%</td>
</tr>
<tr>
<td>North East</td>
<td>7%</td>
</tr>
<tr>
<td>North West</td>
<td>11%</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>2%</td>
</tr>
<tr>
<td>Scotland</td>
<td>5%</td>
</tr>
<tr>
<td>South East</td>
<td>11%</td>
</tr>
<tr>
<td>South West</td>
<td>8%</td>
</tr>
<tr>
<td>Wales</td>
<td>6%</td>
</tr>
<tr>
<td>West Midlands</td>
<td>13%</td>
</tr>
<tr>
<td>Yorks &amp; Humber</td>
<td>9%</td>
</tr>
</tbody>
</table>

This category covers many different conditions. Some will have been diagnosed at a very young age, others in adulthood. Examples include muscular dystrophy, motor neurone disease, Alstrom syndrome, Huntington’s disease and Rett syndrome.

Some 80% of our young adults with organ failure were diagnosed with kidney failure.

We connected with 100 cystic fibrosis health professionals across the UK. Together they referred 140 young adults to our services.
Supporting young adults living with rare diseases

We were delighted when the Alexion Charitable Foundation responded positively to our request to help support 150 young adults living with rare diseases through its Rare Belonging grant programme.

Alexion is a global biopharmaceutical company that develops medication and therapies to support patients living with rare diseases. This felt a perfect fit to Willow’s strategic direction that aims to grow our reach to beneficiaries living with rare and life-limiting conditions whose journeys are often lonely and isolating.

To identify the healthcare professionals that look after these patients, we asked the NHS Lead Commissioner for rare diseases to introduce us to more than 60 lead professionals across the UK who care for patients with rare conditions. We also attended RAREfest22, a two-day rare disease inspired festival where 25 parties involved in supporting those affected by rare conditions came together.

This has led to more than 300 new medical professionals referring patients to Willow for much needed quality time away from illness, treatment, worry and anxiety. Feedback received from the families and their health professionals, has been overwhelmingly positive.

Lewys and Rhodri’s Special Day

Lewys and Rhodri are living with Duchenne muscular dystrophy. They found their way to Willow through the Alexion project. As avid Potterheads, the 21-year-old twins from Wales asked to spend their Special Break at Harry Potter World.

Lewys said: “I am reliant on carers and family to meet my needs, mainly my older brother. I use a powered wheelchair and need to be hoisted out of it. The cost-of-living crisis has affected us like everyone else. The heating bills are a worry as I have a lot of equipment that uses electricity and the heating is on as I feel the cold.”

Our Special Day Coordinator Claire sourced accessible hotel rooms with ceiling hoists. Willow not only purchased entry to the studio and tour, but funded the petrol costs for the family and gave a little extra to buy souvenirs from the studio shop or have a meal out as a family.

“It was great spending time with my family and staying in accommodation that catered for my disability. I thoroughly enjoyed the Warner Brothers Studio experience and would love to return. I had an amazing time, making wonderful memories with my family and took lots of photos to help me remember the day.”

Our strategic goals rest on following three pillars:

Growth
- Our fundraising plan in 2023 aims to raise £3.0M
- Implement our retail growth plan that aims to open two new retail shops in March and April
- Continue to grow our events fundraising area to pre-pandemic levels
- Targeted service promotion to reach priority patients
- Grow the number of beneficiaries supported year on year

Impact
- A continued core focus on delivering uplifting and unique Special Days and Special Breaks
- Deliver a tailored Special Treat service based on feedback from service users
- To provide extra investment into Special Day packages supporting those with complex medical needs
- To demonstrate impact of our services via feedback obtained by beneficiaries and healthcare professionals

Sustainability
- To maximise our fundraising and service resources efficiently and effectively
- To further develop an engagement framework that will encourage long-term involvement from beneficiaries and their families
- To increase Willow’s profile among healthcare professionals
- Continued evaluation of external factors that will impact the environment in which we operate

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