The Charity for Disabled Children

Our Highlights 2022/23

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Introduction

Newlife The Charity for Disabled Children was founded over 30 years ago to ensure that disabled and terminally ill children get the best possible start in life and have the opportunity to fulfil their potential.

As the UK's largest charitable provider of specialist disability equipment, Newlife provides vital equipment to disabled and terminally ill children, as well as information and support to their families and carers.

As a charity we rely on donations and support from a range of sources, including corporate partners, trusts and the wider public.

Our other source of income is through our retail stores, where we work with high street brands to recycle donated stock, giving a new life to clothes which would otherwise end up in landfill.

Why we exist

There are 1.5 million children and young people living with a disability in the UK. In the last ten years the percentage of children and young people with a disability has gone from 6% of the UK population to 11%*. Many families are battling to get the support and equipment they need from local services, often facing long delays to get the assessments and support they need.

Over **90%** of the families we spoke to, all supported by Newlife, told us that without Newlife, it is unlikely they would have been able to get the equipment needed for their child.

Newlife exists because without us, many thousands of children and young people with disabilities would go without.

* Family Resource Survey FY21-22



What we do:

- We provide thousands of children and young people with life-changing specialist equipment.
- We give help, information and support to thousands of families through our free Nurse Helpline.
- We give the gift of play and the opportunity to learn new skills with free loans of specialist sensory toys through our Play Therapy Pod service.
- We campaign and advocate on behalf of children and young people with disabilities, ensuring their voices are heard.
- We provide opportunities for adults with additional needs through employment and volunteering, giving them the chance to learn new skills and interact with others in a positive and encouraging environment.



With the buggy from Newlife we go on different walks. When he gets upset, I will pop him into the buggy and he calms down within two minutes of being in, as he feels secure and settled. It has opened-up possibilities and the world to us.

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Mission, Vision and Values



Our mission

Together we will make life better for disabled or terminally ill children and their families.

Our vision

That every disabled or terminally ill child and their family, get:

The equipment they depend on; the quality of life they deserve; the caring support they need and the chance to fulfil their potential.

Our charitable activities

Newlife changes the lives of disabled and terminally ill children across the UK. We grant or loan thousands of items of equipment every year, often in emergency situations.

We provide information and support to families through a dedicated Nurse service. We campaign to give disabled children and their families a voice and we fund medical research to give hope for the future.

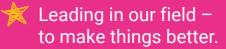
A review of how we met our objectives for the year are included in our detailed review of services to follow.

Our Values



Always compassionate and deserving of trust – in all we do.

Making things happen – for those we serve.



People at our heart – every day.



We were very anxious about going home from hospital without a specialist bed. The bed provided by Newlife has really helped us. It is so reassuring - Oakley is settled and comfortable and sleeps well and we can sleep too.

Our year in numbers 2022/23

At year-end, we provided 13,802 instances of help to disabled children and their families, a 25% increase on our target of 11,000 for the year and a 55% increase on the previous year (8,890). We responded to the growing demand for services by increasing our spend on specialist equipment from £1.46m in 2021/22 to £2.53m in 2022/23.

385

children were provided with help in an emergency with an equipment loan.

94

we gave equipment to children who were in need in 94 of the 105 counties in the UK.

£1,923

is the average cost of a piece of specialist equipment provided through our grant service.

1,524

children received specialist disability equipment such as wheelchairs, buggies, walking frames and communication aids through our grants service.

<u>10,898</u>

instances of help through our dedicated Nurse helpline.

5

the average age of a child benefitting from our Play Therapy Pod service.

£2.53m

the value of specialist equipment (loans, grants & PTP's) we provided to families.

1,380

the number of Play Therapy Pods supplied direct to children at home, to support their learning and give them a chance to play and smile.



The first time Gabriella sat up and played with her brother Samuel, I cried. The sensory toys have really helped to stimulate her interest in playing.

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Emergency Equipment Loans



Newlife is the only national charity providing emergency specialist equipment to disabled children in crisis.

Many families struggling with the impact of the cost-of-living crisis cannot afford the vital equipment they need and many local areas have substantial waiting lists, and fewer professionals to help than before.

We have heard from families who have waited more than 12 months just to get an assessment for the equipment they so desperately need.

Many children and young people with a disability simply cannot afford to wait. We know the importance of receiving the right treatment, intervention and care at the right times, especially if and when crisis hits, and our Emergency Equipment Loan service aims to provide essential equipment as quickly as possible when it is needed.

The highlights:

• Children can sleep safely at home with the specialist beds they need.

- Children can enjoy the outdoors and be comfortable with a specialist buggy loan.
- Children are no longer stuck in hospital because they don't have the specialist equipment they need to be discharged.
- Life-limited children and their families can create memories and enjoy precious time together with the essential equipment they need.

Our target was to continue to help children and families by providing emergency loans to those families most in need.

In 2022/23, we provided **385** (2021/22 574) Emergency Equipment Loans at a cost of £290,024.

The emergency loan of a specialist buggy was a 'godsend' to the family of one-year-old Roman Pearse, as it allowed them to leave the house while they waited for a specialist buggy from their local authority.

Roman has quadriplegic Cerebral Palsy, cortical vision loss and complex epilepsy, meaning he can't sit up, crawl or roll over unaided. Although he wanted to sit up and see the world around him whenever he was in his standard high street buggy, it didn't provide the support he needed. Roman slumped to one side, making him very uncomfortable and risking long-term damage to his joints and muscles.

As the Plymouth family faced a wait of around a year to receive a specialist buggy from their local health and social care services, the family turned to Newlife to bridge the gap with the emergency loan of a specialist buggy to meet all his needs and protect him during seizures. This meant that Roman could be safely taken to medical appointments and into the local community.

Mum Lauren said:

"The loan buggy from Newlife means we have been able to take him everywhere we need to go and he's enjoyed trips to the zoo and the aquarium too. It gives him the opportunity to spend a good amount of time away from home and helps his development, without us having to worry about the impact on his joints and posture – and it means Roman can just have a good time while we are out. **Case story**



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He gets so excited when he sees us get the loan buggy out now. Having this has been a godsend and has made all our lives so much easier!

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Equipment Grant Service

Newlife believes that all children should have the chance to fulfil their potential and live their best possible life.

Unfortunately many children are missing out and don't get the equipment that will make a huge difference to their lives and that of their families. This equipment can help a child in so many ways, for example, reducing pain, improving mobility, communication skills or sleep, and often improves quality of life for the whole family. With more families struggling financially our services are needed now more than ever.

We provide equipment grants that can be fast-tracked in urgent situations as well as through our 'quality of life programme', enhancing young lives and giving children the chance to be the best that they can be.

Our target for the year was to increase our quality-of-life equipment grants to help children live their lives to the fullest potential. We know equipment can empower, providing opportunities to talk, walk, go to school or higher education and to enjoy precious time with family and friends.

This year we provided 1,139 (2021/22 574) equipment grants of which 855 (2021/22 333) were fast tracked because they were urgent.

Newlife secured funding to support families during the cost-of-living crisis through its Family Essentials Fund, which provides practical everyday items that we know families often have to forego in order to cover basic living costs.

The impact:

- A powered wheelchair enables a child or young person to go to school, college or university.
- A child is able to sit and eat at the table with their family because of their special seat.
- A communication aid enables a child to tell their parent they love them for the first time.
- A child is able to walk because of their specialist walking frame.
- A child's condition will not get worse, preventing the need for surgery at a young age because they have the right chair or bed to support them.

It has been estimated that it costs 3 times more to raise a child with a disability*. Families have to spend more on fuel to get to hospitals or special schools; and families use more energy as they may have to keep their house warm all year round. Disabled children are also more likely to live in poverty than non-disabled children*.

The Family Essentials project was initially launched as a pilot during COVID-19 when we recognised that disabled children and families living in poverty would be hardest hit by the restrictions and changes to daily life during the pandemic. We know that this project has huge impact and provides real, simple and practical support to families in need. During the period Nov 22 - March 23 79 essential items were provided to families identified as most in need.

Connie's story

Six-year-old Connie Annakin, from Leeds, was diagnosed with a form of childhood dementia called Battens Disease when she was aged three. Over the previous months she had developed seizures while losing the ability to walk or talk.

Devastatingly, her parents Caroline and Rob were told most children diagnosed with the condition pass away between the ages of six and ten.

Connie receives a revolutionary new enzyme treatment, administered at hospital through a port in her brain twice a month, but travelling to treatments - or anywhere - was made difficult by the basic wheelchair Connie had. It was too small, didn't support her head or recline so she could sleep, or keep her comfortable during seizures. In desperation her family applied to Newlife for a specialist buggy.

Now. Connie can attend medical appointments easily, safely and comfortably - and have as many visual experiences as possible, before her sight fades completely.

Mum Caroline said

"The buggy Newlife helped provide has been life changing. The enzyme treatment is working well, and we are hopeful it will stop her developing further disabilities, but it can't give her back what has been lost, so she needs the right specialist buggy to go anywhere safely. The treatment can't halt her loss of sight either, as it can't cross the blood-retina barrier, so having this buggy is vital to see as many different things, such as the ocean and Christmas lights.

* Scope 2019

Case story



Connie can no longer tell the difference between day and night, so it's imperative she can recline to be able to sleep whenever she needs to, as lack of sleep can trigger more seizures. The tyres on the buggy can handle all terrains and the buggy even has weatherproofing we can use.

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Now we can go anywhere we want and give her all those great experiences and live in the moment so we can make memories.

^{*} UK Poverty 2023, Joseph Rowntree Foundation

Play Therapy Pods

The gift of play should not be underestimated. Specialist toys can be so expensive and yet they can help a child in many ways.

Newlife's Play Therapy Pods give disabled children from across the UK the chance to learn and smile. Our free loans of specialist toys improve learning and help children gain crucial key skills that support them through life. They help children interact with parents, carers, siblings and friends and support smiles – which in the face of painful or debilitating conditions can be rare.

Newlife provides specialist development and sensory toys for a 12-week loan period. Toys are suitable from birth right through to 18 years of age.

Each pod contains a selection of specialist toys that can teach cause and effect, assist with developing hand-eye coordination and promote understanding of balance and movement, as well as helping with the development of motor skills and stimulating audio and visual senses. Having access to the right specialist toys enables disabled children to better interact with the world around them.

The Play Therapy Pod Service also gives children and their families the chance to try a range of different toys, so they can discover which toys best suit their child's needs before making an investment or buying toys as a gift.

The target for 2022/23 was to look at opportunities to grow the Play Therapy Pod service, including whether we can introduce new types of pods with brand new toys and resources, or work collaboratively with



organisations to help more disabled children and their families.

In 2022/23, we provided **1,380** (2021/22 1,499) Play Therapy Pods.

The impact:

- 84% of families told us their child had enjoyed playing more than ever before after receiving a Play Therapy Pod.
- 92% of families had a better understanding of which toys would suit their child's needs.
- 92% of families said they were 'satisfied' or 'very satisfied' with our Play Therapy Pod service.

Winifred's story

Four-year-old Winifred Keuthen can now spend time playing and bonding with big sister Emma, thanks to Newlife's free loan of specialist sensory toys to better meet her complex needs.

Winifred, known as Winnie, had a traumatic start in life which made survival rather than play a priority. As she grew it became clear it was difficult for her to play with standard toys, which could hinder her development.

Born prematurely, Winifred, has a complete heart block and has a pacemaker. She also lives with Cerebral Palsy and global developmental delay, meaning she is unable to walk and is nonverbal. It is difficult for Winifred to play with standard toys due to her complex conditions, so her family turned to Newlife, who provided Winifred with a Discovering Sounds Play Therapy Pod to explore.

These toys have helped with her cognitive and motor development, as well as her social and communication skills. The toys have also had a huge impact for the family, giving Winifred and her older sister Emma new ways to play together.

Mum Annika said:

"Winnie was struggling to play with standard toys as she didn't engage with them, so it was difficult to know which toys to buy for her that she would interact with to help with her development.

"It has really helped us trial which toys will support Winnie's needs, and there is a great selection of toys for her to try different things and explore.



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The best part is how the toys have helped Winnie and her 13-year-old sister Emma play together. It is lovely to see them playing together on the musical toys, having competitions around who can hit the buttons faster. It's so exciting for them both to see the box of new toys and to open it together, and it's been a great way for them to bond and have happy family time.

Family feedback – creating a lasting impact for disabled children and their families

"It was absolutely transformational. The difference between not being able to leave our house at all and being able to go safely on day trips and access all of the medical support and therapy Emily needs."

"We can't stress enough how this buggy helped our daughter and our family. Without this buggy it was impossible for us to have days out."

"Literally life changing! It has helped me so much as a single mother with two kids with special needs."

"The equipment has been life-changing for us as a family. We are now able to enjoy family days out and access the community safely."

"The Play Therapy Pod Loan scheme is phenomenal and makes a big difference in my son's communication interactions."



"I really appreciate all the help Newlife has provided us as a family. They've helped to increase the quality of our lives."

"The car seat has made a massive difference in our family life we're able to travel in the car without fear of injury."

"With the equipment my son can continue developing his communication skills. I can see his happiness which is the most important thing in our whole family."

"It has really helped us to find appropriate toys for Isla that work well. We spend a lot of money on specialist equipment, only to find that sometimes it doesn't work."

"Play is something that every professional says is 'vital', but it is tough to know where / how to start with a special needs child. These play pods give you a place to get started, see what your child does and doesn't like and go from there. This is crucial when toys are so expensive."

Our impact in 2022/23

Our impact measurement work carried out in 2022/23 has demonstrated that our equipment programmes make a significant difference to the lives of disabled children and their families.

Families consistently tell us that the equipment provided, whether a grant, loan or play therapy pod, has made a significant difference to the health and wellbeing of their child as well as that of the whole family.

98%

of families said that it is unlikely they would have got the equipment or support needed without Newlife.

93%

of families told us their child was safer as a result of being provided with their specialist equipment.

96%

of families said they were more able to deliver care to their child after receiving equipment from Newlife.

98%

of families receiving equipment said they were satisfied or very satisfied with our service.



of families had a better understanding of which toys would suit their child's needs.

9/10

families said the whole family felt less isolated and were able to go places they needed or wanted to go after receiving equipment.

84%

of families told us their child had enjoyed playing more than ever before after receiving a Play Therapy Pod.

8/10

families who received a specialist bed said their child was sleeping better than before.

Nurse Helpline

Newlife's dedicated helpline is staffed by specialist nurses who are there to help families in need, whether they are struggling with a recent diagnosis and need information and support, or are facing day-to-day challenges of their child's needs.

No two families have the same needs, so the information and support is tailored to each child and family.

Parents and professional carers can talk to Newlife's nurses about anything regarding a child's condition – and sometimes they might just need someone to listen with compassion and without judgement. Newlife's Nurse Helpline is here to help.

Many families continue to feel isolated and abandoned, unable to speak to professionals as there is a shortage of key professionals with many vacancies currently unfilled. Many of these families turned to Newlife, and our dedicated team.

We're proud of our dedicated nurses, professionals and the team around them, who are there when families need them the most.

In 2022/23, we provided **10,898** (2021/22 6005) instances of help through our dedicated Nurse Helpline.



Heather Lowe said: "When I called the Newlife Nurse Helpline about a specialist car seat and buggy for my daughter Elizabeth they were so supportive and non-judgmental, they were really good. I had tried other charities without success, but when I called this helpline they guided me through everything I needed to do for Elizabeth and even gave me a follow up call to make sure everything was ok, which was lovely, I can't thank them enough."

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It was really traumatic, awful time. Harpers diagnosis was life-changing and we were all very emotional. The Newlife Nurse we spoke to was so sympathetic and calming – it was as though she could hear in my voice I just needed someone to talk to.

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Campaigning



Campaigning – 'giving a voice to disabled children and their families.'

Research shows that it has never been harder than it is right now for disabled children and their families.

The March 2023 Failed and Forgotten report, produced by the Disabled Children's Partnership, found that only 1 in 5 families received the support needed to enable their child to fulfil their potential.

Through our campaigns, we offer families a voice by working with local and national decision makers to overcome barriers, change laws and help set up policies that lead to better and more suitable equipment provision for all children.

Campaigning – Nationally, what did we do?

From looking for opportunities to influence policies that support disabled children to thrive, to supporting the national development of disability services, we are well placed to support the disabled children and their families as one of the leading experts in children's disability equipment.

We continue to work with our families to truly understand the issues that they face and by working with key local and national decision makers.

Successes include:

- We tabled an Early Day Motion on mobility support for terminally-ill children under 3 which was supported and signed by 21 MP's.
- Alongside other organisations, we raised issues surrounding the additional costs families with disabled children incur to MP's which was then acknowledged by the Prime Minister.
- We submitted a response to the government consultation on reviews of education, health and care plans (EHCPs) which looked at how local authorities review an individual's EHCP.
- We held a series of meetings with key parliamentarians for Cannock Chase and Minister for Asia – FCDO.
- The All-Party Parliamentary Group on equipment for disabled children met once during the financial year with Newlife to carry on as the secretariat.



A member of parliament tabled a number of written questions to government on a variety of issues including:

- To ask the Secretary of State for Health and Social Care if he has plans to implement care pathways for the provision of equipment for children and young people with complex needs, similar to those provided for under the Joint Protocol for the Provision of Children's Equipment in Scotland.
- To ask the Secretary of State for Work and Pensions how many children under the age of three are receiving the disability living allowance care component under special rules in England.
- To ask the Secretary of State for Health and Social Care what the plans are to tackle delays in provision of community health services for children and young people as a result of covid-19.
- To ask the Secretary of State, what the plans are to enforce the duties for assessment of children in need that local authorities must meet, as outlined in statutory guidance.

Looking forward

We will focus on the following campaign objectives:

1.

Call on UK and devolved governments to publish a national circular reminding local authorities and health bodies that all disability equipment should be assessed and provided based on the needs identified.

2.

Call on UK and devolved governments to recognise the lack of current professionals and work on a solution to share top down to local authorities around more funding for professionals or ring-fence existing funding.

3.

Continue to provide Secretariat to the All-Party Parliamentary Group on Equipment for Disabled Children.

4.__

Ahead of the general election, continue to work with our service users and professionals to identify the needs of disabled children and advocate for them within local and national policy.

Volunteering

There are so many ways in which volunteers play a vital role in supporting Newlife.

This can be by helping us to process the stock we receive so that it can be sold in our Newlife stores or online; by volunteering in our retail stores; or by helping us to clean, prepare and send out Play Therapy Pods to disabled children and their families.

People volunteer for many reasons and the benefits are wide-ranging: from the feeling of making a difference, to joining a team and making new friends, or learning new skills and gaining valuable career experience. Volunteers are supported and involved in inductions, briefings and thank you events throughout the year.

Volunteering at Newlife is an exciting and fulfilling opportunity. Not only can volunteers gain new skills, confidence and experiences throughout the volunteering journey, but our volunteers also make a huge difference to the lives of disabled children and their families across the UK.

In June 2022 we hosted our 3rd Volunteer Awards event. The Thank You Volunteer Awards brought together volunteers and staff members from across the organisation in an evening of celebration and laughter.

Well done to our fantastic volunteers.

Skills and integration for disabled adults

When children with disabilities grow, they often need a hand into work or help with social integration. Newlife offers disabled adults opportunities to volunteer, helping the charity alongside members of staff and other volunteers to process goods for retail and recycling and to help us raise funds.

Since Newlife became a CIO in 2016, this has become a new object of the charity and is part of our constitution. We believe it is crucial to give disabled young people and adults, who can easily be excluded from society on grounds of their disability the support, training, workplace experience they need. We ensure our volunteer opportunities take place in an inclusive, safe, social and happy environment.

Our target was to increase volunteer hours for the year and increase volunteering opportunities for all, including adults with disabilities and additional needs. Our volunteering programme helps volunteers to develop new skills, meet new people and create new opportunities as well as ensure more people can benefit from the gift of volunteering. At a glance:

The highlights:

- **144** volunteers gave 13,892 hours to Newlife in 2022/23. This was a increase on last year's figures of 124 and 12,655 respectively.
- Over **4,500** volunteer hours were given by adults with additional needs. This is 7.14% of the total up from 4,200 in 2021/22.

Fundraising

Fundraising income for the year achieved £2,067,173 (2021/22 £1,481,632). Fundraising activity continued to grow with a focus on transforming the level, predictability and sustainability of philanthropic income. Developing corporate partnerships and growing our donor pool.

Key achievements in the year included:

We successfully secured funding from the Motability Foundation and were awarded just under £1M. The Motability funding is part of a new grant scheme to improve mobility and access to wheelchairs for disabled people and Newlife was one of the first recipients of funding. This transformational grant will provide wheelchairs and buggies to over 280 children and young people across the UK over the next 3 years.

The Marian Elizabeth Trust pledged another 4 years of funding towards the Play Therapy Pod service totalling £400,000. This will take their total gift amount to £1M.

The 2022 Christmas campaign, Give the Gift of Play, achieved £35,178, a 35% increase on the original budget and a 223% increase on 2021.

Income was secured from 18 new charitable trusts in the year. We were grateful to receive donations from two new donors The Peter Harrison Foundation and Masonic Charitable Foundation who gave gifts towards our equipment services.

We received two legacy gifts in the year, totalling £94, 737.



Priorities for 2023/24 are:

- Grow our individual donor pool and develop our stewardship pathways for donors to give regularly and at larger giving levels.
- Grow third-party fundraising, including families and their networks, and develop a range of events and activities for supporters to take part in.
- Continue to maximise our corporate partnership network and develop corporate volunteering opportunities.
- Engage store customers and strengthen the charity message to improve awareness.
- Develop and strengthen relationships with charitable trusts and foundations.

Retail

Newlife is the trusted long-term partner of many major retailers, manufacturers and brand holders in the UK and Europe.



Joining forces with well-known high street brands has allowed Newlife to do something unique: sell brand new clothes at a fraction of the original price.

Brands play their part by donating surplus stock, increasing its lifespan and preventing it from ending up in landfill. And every purchase made in Newlife stores or online makes a difference, with 100% of our profits going to help disabled children and their families access much-needed specialist equipment.

Further charity fundraising takes place at till point with round-up donations, which for 2022/23 totalled **£51,416**.

The highlights:

- The retail operation saw further expansion with the opening of a new flagship store in High Wycombe. The biggest in Newlife's portfolio opened on July 28, 2022.
- There were several first anniversaries celebrated across the portfolio with Yeovil, Newlife Discount Plus and Newport all turning one.
- The Marketplace concept has been extended to Newport and Burton stores.
- New customer Style Card signs up totalled 9,821 in 2022/23.



Environmental impact

What does Newlife do to protect the environment?

We divert thousands of unrequired commercial products from landfill and incineration. We work with many well-known and wellrespected high street stores, designer labels and supermarkets to help them reduce waste by finding ways to reuse or recycle it. Newlife has a clear objective in its in its constitution to protect and preserve the environment for the public benefit through waste reduction, reuse, reclamation and recycling.

How do we do this?

We take stock such as clothing, bags, shoes, accessories, soft furnishings, electrical items and homewares that are no longer wanted/ required by UK and European retailers. We organise to pick it up from location if required.

We then assess the stock through our warehouse operation, to see if it can be re used. If so then we will remove the labels in line with donors' guidelines and send it to be sold in our retail stores across the UK.

Any items that cannot be resold, we use qualified and trusted partners to recycle or repurpose as much as possible often to create new products.

Thank you to all our retail partners who are helping to make our work possible.

The recycle and re-use of this product sits within Newlife's commercial division. All profits from the commercial division are spent on our charitable aims, helping to change the lives of disabled and terminally ill children.

Our target was to rescue more stock and reuse it, to extend it's life, reducing the environmental effect and creating a sustainable income source for the charity.

Newlife's net carbon savings from donations in 2022/23 was equivalent to carbon emissions from over 23.9 million road miles by average cars.

*Source: Newlife's Carbon Footprint estimate report by Resource Futures 07/08/23

The highlights:

In 2022/23 the environmental impact of Newlife's reuse and recycling operations saw...

- 1,947 tonnes of items collected.
- 8,304 tonnes of carbon saved.
- Over 970 tonnes of items sold for reuse in 9 Newlife shops in the UK.
- Over 190 tonnes sent to Europe for reuse/recycle saving 1,330 tonnes of carbon.
- Over 540 tonnes of items sent for recycling/fibre recovery.

Thank you for supporting Newlife and enabling us to make a difference to disabled and terminally ill children and their families.

Your support is changing lives and helping open up opportunities to a brighter future.

Do get in touch if you'd like to find out more about how you can help further, we'd love to hear from you.

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