

# Together with friends, family and neighbours

Summer 2023 | Carer insights and updates



Welcome to our third issue of Together with friends, family and neighbours.

With carers and staff, we've made this newsletter to share information from our Trust and local communities.

We work alongside people who care for their partners, neighbours or friends. We know that many unpaid carers may not identify as one, or know they are one. In this newsletter, when we say carers, we mean anyone who provides unpaid support that someone in our care relies on.



## Inside this issue...

---

### Spotlight on

- 4 Carers Week 2023 in pictures
- 6 New video about psychosis makes carers' voices heard
- 6 Film shines a light on how it can feel as a carer for someone in secure services
- 7 Learning Disability Week

---

### Rebecca's story

- 8 Family tragedy inspires Trust worker to help others

---

### Supporting families

- 10 Grant help for group supporting families caring for children with eating disorders

---

### Hazel's TEWV journey

- 12 "Kindness often goes unnoticed, but it plays a silent and powerful role."

---

### Summer celebrations

- 14 Commitment to carers acknowledged with Triangle of Care 2-star accreditation
  - 15 Celebrating 75 years of NHS care
-

# Carers Week 2023 in pictures



Last month we celebrated Carers Week, which took place from 5-11 June. Carers Week is a time to celebrate and promote the incredible dedication of unpaid carers. We also took the opportunity to offer information to carers who may be looking for support.

Across our Trust area we hosted a range of events. Some of these were organised by our Carers Working Group while others were arranged by carers, partners, and staff on our wards and in the community.

On these pages you can take a peek at some of the pictures from across our Trust.

We hope you enjoyed our events, if you were able to attend. We really value your commitment to being a carer. The role you play is invaluable.

**We know that supporting carers is not just for Carers Week. If you ever need information or support, please visit the [Carers' Hub](#) on our website.**





## New videos created with carers

### New video about psychosis makes carers' voices heard

Our Early Intervention In Psychosis team wanted to make the voice of carers heard, partly because they are often absolutely crucial to recovery, but also because carers deserve support and recognition. To do this, they are promoting a video which was created by carers working alongside a professional film maker. We think they've done a brilliant job.

---

You can watch the video on [YouTube](#).

It's named [EiP Care Support MASTER 10mins](#)



### Film shines a light on how it can feel as a carer for someone in secure services

Night Light Theatre Productions and our Trust have been working collaboratively with carers, to produce a new film.

The co-created project brought together carers, colleagues, producers and actors from across the Teesside area. The film is based on the thoughts, feelings and experiences of those whose loved ones are receiving care in secure inpatient facilities. It was created in partnership with Ridgeway, the Trust's secure inpatient service at Roseberry Park Hospital in Middlesbrough.



The film is currently being shown at screenings at Ridgeway. The team are also hoping to make it available to everyone on the Trust website.

## Spotlight on...

# Learning Disability Week

19-25 June was Learning Disability Week - a week to raise awareness of what it's like to live with a learning disability and an opportunity to showcase the support available for people and their families.

Our learning disability services celebrated in many ways, with some choosing to have garden parties and coffee mornings, and others teaming up with partner organisations to hold information events for local people to learn more about support available.

Aysgarth short-term care unit in Stockton-on-Tees held a double celebration with the unit celebrating a historic 40 years in operation with a [fabulous garden party](#) (pictured below, bottom right).

Colleagues from services across Teesside held information events at James Cook University Hospital, University Hospital North Tees and The Employment and Training Hub, in Stockton-on-Tees to raise awareness of local support available (pictured below, top right).

Other colleagues also shared why they loved working in learning disability services. You can [read some of their stories on our website](#).

Members of the Improving Together team in North Yorkshire, York and Selby, came together to support the theme of this year's campaign 'Busting Myths' and shared their view as to what it's like to live with a learning disability and what they want you to know. This is really powerful and you can [watch the short video here](#).

Jody Buxton, learning disability services, modern matron at Ridgeway secure inpatient services in Middlesbrough, also shared how growing up with a brother with severe learning disabilities inspired her 23-year-career in learning disability services. Jody and her brother Steven are pictured below, bottom left. You can [read Jody's full story on our website](#).



## Rebecca's story

# Family tragedy inspires Trust worker to help others

Trust worker Rebecca O'Keeffe has drawn on the tragic loss of her mother to early-onset Alzheimer's to pen a touching book to help children understand the grief around the condition.

Rebecca, who works for our Trust, helped care for her mother Julie when she was diagnosed with the disease at just 51.

"My eldest child was just a baby at the time," she said. "I found it really challenging to explain, as the illness progressed, why grandma didn't recognise him, or why she acted in a certain way.

"When my youngest was born six years later, my mam's illness had significantly deteriorated. However, we still talked about his grandma, to ensure he knew who she was."

## Hoping to help others

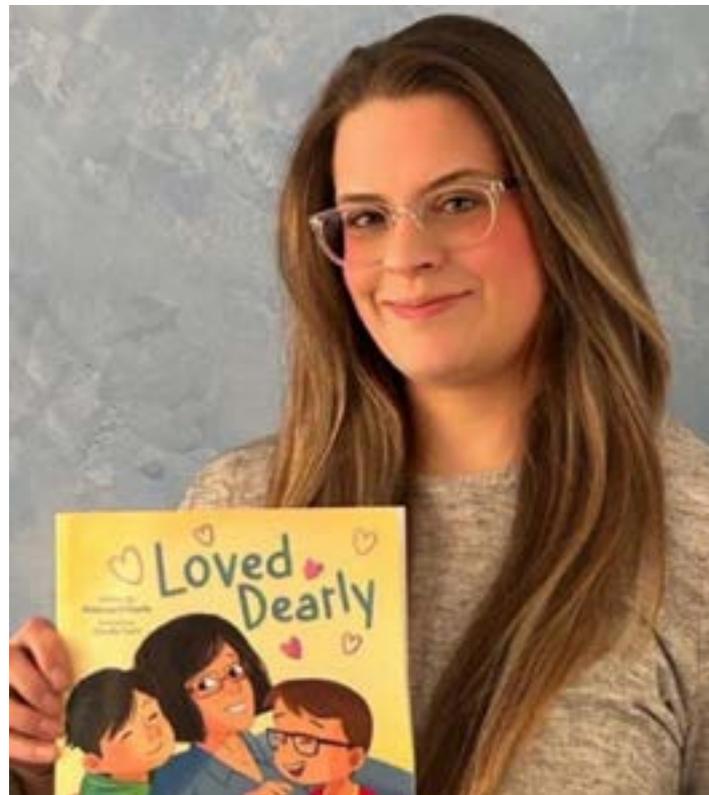
The idea for the book came from the difficulties Rebecca experienced when talking about Alzheimer's – as well as the grief around the condition – with her children.

"As an adult, trying to understand the illness is really difficult, so I wanted to help other families have these difficult and emotive conversations," she said.

"I wanted to help families explain the changes children may see, hear and feel and encourage new ways of enjoying a changing relationship as the illness progresses."

**"I wanted to help families explain the changes children may see, hear and feel and encourage new ways of enjoying a changing relationship as the illness progresses."**

**Rebecca O'Keeffe**



## Small changes provided first warning

Rebecca's mother Julie had been working in admin and logistics for a transport firm, a job which required huge attention to detail, when she first started showing signs of Alzheimer's.

It was small things at first, like losing her keys or forgetting key dates. Then, Julie's co-ordination became impacted, and she found everyday tasks like putting on a coat difficult.

"My mam was such a caring, funny, lovely lady – often the life and soul of a get-together," said Rebecca, a service manager for our Trust's specialist adult mental health services.

## Rebecca's story continued...

"One of the first warning signs we had was when she struggled to understand the 24-hour clock while doing time sheets for work – a task she carried out with ease prior to diagnosis."

Julie, from Spennymoor, was 49 when her family started to notice she was acting out of character – and, at first, she was treated for depression and the menopause.

Two years later she was diagnosed with Alzheimer's.

"The family was devastated when the diagnosis was confirmed," said Rebecca. "We knew something was wrong but were shocked because of her age. It just seemed so young."

### Tragic loss

Julie stayed at home for the first two years after her diagnosis, looked after by Rebecca and her siblings Iain and Hayley – as well as her parents, carers and TEWV health staff.

The time came, however, when she needed to be admitted to Auckland Park Hospital in Bishop Auckland for an in-depth assessment and treatment.

Julie's final few years were spent in a nursing home, where she was cared for by "fantastic staff" as her illness progressed. She passed away last year aged 63.

"With mam, Alzheimer's was not just about memory loss, it was much more – like personality changes and the psychological and emotional impact on her and the family," said Rebecca.

"It's such a difficult situation. A loved one may act very out of character – they may get angry, frustrated, confused, when previously these behaviours have never been seen.

"It can be really upsetting for children and adults to see and understand. The idea for the book came to me because I wanted to share our family's experience to support others."

### Hoping to help

Rebecca, who lives near Durham, started writing her book – *Loved Dearly* – in the weeks after her mother's death, working closely with Child Bereavement UK on the project.

The book, which is written from a child's perspective, provides insights into the potential challenges around Alzheimer's – including memory difficulties and behavioural changes.

"It felt like therapy to write it," she said. "We are good at giving other people advice, but not always good at following it. It really helped me to write everything down.

"I think mam would be over the moon with the book. She was always helping others, and I think she'd like that her story will help other families."

---

Rebecca's book *Loved Dearly* is available to buy via Amazon. See here: [Loved Dearly : O'Keeffe, Rebecca, Cerri, Claudio: Amazon.co.uk: Books](https://www.amazon.co.uk/dp/1851828000)





*Kick Rexi Out volunteers – left to right: Jane Blacklock, Sarah Steele, Donna Foster, Millie Easton and Claire Taylor*

## Grant help for group supporting families caring for children with eating disorders

An “inspirational” group launched by the parents of a teenager who became seriously ill with an eating disorder has been awarded a grant to help others in the same situation.

Donna and Paul Foster set up Kick Rexi Out, a support group for North Yorkshire families managing life with an eating disorder, after one of their children was diagnosed with anorexia last year.

The project, backed by our Trust partner the Community Mental Health Transformation (CMHT) programme, as well as North Yorkshire County Council Stronger Communities and Carers Plus Yorkshire, offers practical help and advice.

However, Donna – who now runs the group with a team of volunteers – ultimately aims to turn Kick Rexi Out into a charity, providing emotional and financial aid to those in need. A new grant from the CMHT will help with this.

### Offering a helping hand

“We are not professionals, we are not here to diagnose or treat a child, we are here to support

families through what we know is a very tough time,” said Donna, from Wombledon.

“Ideally, if we got charity status, we could help even more – like paying for a taxi to get to appointments or helping out with a utility bill or shopping. Something to ease the burden.”

Donna and Paul knew nothing about eating disorders until one of their daughters stopped eating last year. The condition came on fast – possibly exacerbated by the COVID-19 lockdowns.

“It ripped through our family at speed. The anorexia in our house became known as “Rexi”. She was like another person taking over our daughter’s thoughts and actions,” said Donna.

“Rexi is vile and very nasty and made our daughter extremely poorly. She exercised for hours, slept little and just stopped eating by the end. It was an awful, terrible time.

“Having our daughter admitted into a specialist care unit was the last resort, but it saved her life.”

## Supporting families story continued...

### Vital support on offer

Donna and Paul launched Kick Rexi Out following their daughter's diagnosis, to offer information and support to parents who find themselves in the same situation.

The Ryedale-based group has now been awarded a £1,820 grant from the CMHT programme towards its work – to help fund a laptop, leaflets, posters, meetings and a website.

Members are also very appreciative of the support provided by Carers Plus Yorkshire, which is helping to advise on ways to turn the project into a charity. A grant has also been obtained from the Bright Sparks group as well.

"Kick Rexi Out is really going from strength to strength," said Donna.

"We want to thank both the CMHT and Bright Sparks for the grants, which are amazing – as well as everyone else who has helped us.

"The next step is to put together a detailed information pack for parents and carers about eating disorders, as well as hold support sessions for people who end up in our situation."

### Eating disorders put strain on families

Donna knows that the journey ahead will not be all plain sailing – but is determined to ensure that others in the same situation will be able to turn to the group for support.

"The strain the illness puts on a family is huge – both emotionally and financially. But Kick Rexi Out can help – carer to carer, and parent to parent," she said.

"The ultimate goal is to work alongside the NHS to help improve the support available to parents and

eventually fund a community nurse. Together we can really change things."

David Kerr, the CMHT programme and delivery lead for North Yorkshire and York at Tees, Esk and Wear Valleys NHS Foundation Trust, praised the work of Kick Rexi Out.

### Inspirational work

"We're delighted to support Kick Rexi Out. The group is doing amazing work which aligns well with the aims of the CMHT programme to increase and improve access to services," he said.

"We want to link services across the whole system together. The ultimate aim is to reduce barriers to

access and ensure services are provided in the right place at the right time."

Paddy Chandler, the Stronger Communities delivery manager for Ryedale and North York

Moors, also praised Kick Rexi Out and called it "inspirational".

"Their aim to support others, and in the long term to help improve systems, fits incredibly well with Community Mental Health Transformation objectives," he said.

"It's great to see Bright Sparks investing in, and giving confidence to, new grass roots community projects. This provides hope and motivation for everyone involved in CMHT and, most importantly, others facing the challenges of the effects of eating disorders."

---

**If you live in the Ryedale area and would like to contact the group email [kickrexiout@gmail.com](mailto:kickrexiout@gmail.com), message via the group's Facebook page or ring 07425 346936.**

### "Kick Rexi Out can help – carer to carer, and parent to parent..."

**Donna Foster**



## Hazel's TEWV Journey

**“Kindness often goes unnoticed, but it plays a silent and powerful role.”**

By Hazel Griffiths, a TEWV governor for the past seven years, carer advisor to the Trust for the last 10 years, family carer, retired emergency department nurse and campaigner.

### **“It ain't what you do. It's the way that you do it”**

This lyric helps to me to reflect on how I listen, interact and communicate with others. Alongside my own values:

- personability
- being non-judgemental
- compassion
- a positive can-do attitude
- belief in equity
- teamwork
- kindness.

Kindness often goes unnoticed, but it plays a silent and powerful role. Be kind.

### **Campaigning to improve the lives of autistic people and their families**

I reflect on the report of the independent investigation led by Bill Kirkup on maternity services. He didn't make recommendations as such, instead he talks of failures of compassion and listening, dismissive and uncaring attitudes, denial and deflection.

I'm a carer for my autistic son and other family members with other conditions. My autistic son is where I get my inspiration, my energy, my tenacity and resilience. He is the reason I've campaigned since Winterbourne View, where we saw public

and political outcry about the dehumanising of autistic people. I believe standards of care should never be lowered for anyone. Standards we walk past become standards we accept.

Sadly, Winterbourne is not an isolated case. I work to improve the lives of autistic people and their families, after my own son experienced poor care, although not in TEWV.

### **For decades autistic people faced discrimination and still do**

Autism is the only long-term condition that has specific legislation in England, with the introduction of the Autism Act in 2009. For decades autistic people faced discrimination and still do, along with health inequalities. Some autistic people don't see themselves as disabled and in need of support. Support can be many things, maybe like acceptance, awareness and reasonably adjusted, accessible and welcoming services.

**“My autistic son is where I get my inspiration, my energy, my tenacity and resilience.”**

Some autistic people do need some extra support to reduce the impact our society, and world has on them. I'm very much for the strength-based approach – less deficit thinking

for autistic people and really challenging that negative narrative, as well as self-reflecting on our own attitudes and behaviours.

## Hazel's TEWV Journey

### Building the right support

I've played a huge part in building the right support for autistic people. I was on the original team with Sir Simon Wessely, who was appointed to look at reforming the Mental Health Act. I asked him to remove autism from the Mental Health Act and redefine what we mean by 'mental disorder'. Autism is neurodevelopmental, not a mental illness. Another important part of the Mental Health Act reform is to have statutory principles, choice, autonomy, the least restriction, and a clear therapeutic benefit.

Autistic people are overrepresented in our criminal justice system. I represent autistic children and young people who are excluded from school, segregated from their peers and play, causing them huge trauma. Often these children need the right support and environment, early intervention and mental health crisis prevention – not punishment.

### We pushed for mandatory training in autism

I'm also a good friend of Paula McGowan (Multi Award-winning activist who has dedicated her life to campaigning for equality of Health and Social Care for Intellectually Disabled and or Autistic people). I've worked alongside her, after her she lost her son, Oliver, to a preventable death. Together, so many people have helped produce Oliver McGowan Mandatory Training – providing healthcare workers with the right skills and knowledge to give safe, compassionate and informed care to autistic people and people with a learning disability. We pushed for mandatory training in autism and this is now law. The [Oliver McGowan draft code of practice](#) is on gov.uk.

### My TEWV journey has been rewarding

I've worked alongside some fab staff, both in designing services and recruiting, interviewing and training across all job grades and departments.

Earlier in the year, I helped train our new healthcare assistants (HCAs) and some international preceptorship nurses. I said at the end of my talk how rewarding it is to work alongside patients and colleagues and that I am getting on now and passing the baton on to them! I thanked them for choosing to come and work at TEWV. I said we have some issues, which we're learning and improving on, that I've trained thousands of our staff and that we have some amazing staff. I got round of applause!

One of the best bits of feedback I got was from a young HCA. I could see her writing down the resources and notes. At the end when I asked if anyone had any questions or comments, she said: "You have helped me write my essay". I said: "Here, I want credited in your essay."

We both laughed. I loved her energy. I ask us all to keep curious, compassionate and keep learning.

I have so many teams to thank, including our involvement and engagement team, who do a fabulous job.

Finally, I want to raise awareness around family carers. We're there when our loved one is well, in crisis or ill. We're not very good at looking after ourselves and many, on top of their caring role, campaign and get involved with the trust. So, a huge thanks to them.

**"We're there when our loved one is well, in crisis or ill. We're not very good at looking after ourselves and many, on top of their caring role, campaign and get involved with the trust. So, a huge thanks to them."**



## Commitment to carers acknowledged with Triangle of Care 2-star accreditation

We're delighted to announce that we have maintained our Triangle of Care accreditation with a 2-star rating. This ongoing recognition is a testament to our commitment to involving and supporting carers.

The Triangle of Care, an initiative from the Carers Trust, aims to improve the quality of care and support for patients and their carers. It highlights the importance of collaboration, communication, and involvement of carers as equal partners in the care and treatment process. Our 2-star accreditation highlights our work to identify carers, having carer experience as one of our overarching goals, and working with partners and other organisations to support carers.

**“Our 2-star accreditation highlights our work to identify carers, having carer experience as one of our overarching goals, and working with partners and other organisations to support carers.”**

The Carers Trust noted many aspects of our submission including:

- that carer support organisations attend our inpatient wards
- that carers were involved in creating our Carers Hub website.

We acknowledge that carers play an indispensable role in the wellbeing and recovery of people in our care. By maintaining our Triangle of Care 2-star

accreditation, we reinforce our commitment to nurturing a compassionate and inclusive care environment that values the contribution of carers and recognises their needs.

We look forward to building upon this achievement. We remain steadfast in our mission to provide a great experience for carers, as well

as patients, partners and staff.

## Summer celebrations



5 July marked 75 years of the National Health Service, NHS75, a milestone that was celebrated by NHS staff and those that use our services up and down the country.

In 1948, when the NHS was first created, it was the first universal health system to be free to all at the point of entry, and the service's core values that we hold so close remain as important today as they were then. NHS services continue to evolve and adapt to meet the changing needs of different generations and a growing population, and we are proud to be part of this much-loved institution.



Many of our departments and teams held events to celebrate NHS75, as you can see in our fantastic pics.



We have a lot to be proud of, yet we don't always provide a good enough experience.

**In 2020  
you told us...**

**1 Our purpose...**

For people to lead their best possible lives.

**We want to be...**

We will co-create safe and personalised care that improves the lives of people by involving them as equal partners. We will listen and always be respectful, compassionate and responsible.

**4 We can achieve this by always living our values:**



Respect



Compassion



Responsibility

**5 Our three big goals**

**Goal 1**

To co-create a great experience for our patients, carers and families:

- Outstanding compassionate care, all of the time.
- Access to the right care for you.
- Support to achieve your goals.
- Choice and control.

**Goal 2**

To co-create a great experience for our colleagues:

- Pride because your work is meaningful.
- Involved in decisions that affect you.
- Well led and managed.
- Workplaces that are fit for purpose.

**Goal 3**

To be a great partner:

- Share an understanding of our communities
- Work innovatively across organisational boundaries.
- Be recognised for what we have achieved together.

Your opinions are important. Get involved