

Keech Matters

SPRING 2021



**URGENT
APPEAL**

We need your help
to *keep Keech caring*
during our 30th year.



It's been a year since we were last able to send you Keech Matters – a year in which coronavirus has had such a huge effect on all our lives. I hope you and your family are safe and well as we – hopefully – start to get back to some kind of normal.

This year, Keech Hospice Care celebrates the 30th anniversary of its opening and it's really awe-inspiring to see everything we've achieved (page 5), including through the pandemic. I'm so proud of how our frontline teams have cared for unprecedented numbers of patients, including patients with COVID-19, both at the hospice and in people's homes.

The pandemic has had a devastating impact on our fundraising and shop income, so we have had to launch an urgent appeal to Keep Keech Caring. Please take some time to read (opposite) why we need your help now.

We're determined nothing will stop our vital care and we're looking to the future. On page 14, discover the fun, family-friendly post-lockdown events we're planning including something very special: a 'thank you' gift to our community for all their support over the last 30 years.

Stay safe and well!

Liz Searle, CEO



Scan here to look back at Keech Hospice Care over the past year.

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URGENT APPEAL

When the coronavirus hit last February, little did we know the far-reaching, life-changing impact it would have on how we go about living our daily lives.

At Keech that saw us proudly continuing our care for adults and children - and support for their families - in unprecedented numbers, while having to adapt to how our nurses and doctors provided that care.

At the same time, the closure of our hospice shops and cancellation of fundraising activities had a devastating impact on our income. We were overwhelmed by the love of the community who supported us in all manner of ways.

But as we plan for the months ahead, we're looking at a significant shortfall on our income. That's why we launched our first ever urgent appeal in February, to help us continue caring right now and through the year - and to ensure that we'll be here for you, your family and friends, when you need us.

You may have received the appeal we sent out, seen or heard us on TV or radio or on social media. If you've responded thank you so much! Once again we've been touched by the response and just how much Keech matters to you.

If you haven't responded – and your circumstances allow you to – you can support our care and help keep Keech caring by donating online at www.keech.org.uk/urgent or to donate **£10** text **'URGENT'** to **70470**. (Texts cost £10 plus one standard rate message.)



Scan to download.

Introducing the new Keech Connect app, the new easy way to donate!

Keep up to date with all our news, events and even track donations. Free to download from your preferred App store you can keep connected with everything Keech!

NEWS IN BRIEF

What's been happening at Keech Hospice Care.

"We're still here, still caring, at the hospice and in patients' homes, often in new, innovative ways." Elaine Tolliday, Clinical Director

Coronavirus brought huge changes in the way we deliver our care. One year on, we're still developing and adapting so we can #KeepKeechCaring.

In-patient and community teams - on the frontline since the start - care around the clock for patients, many with Covid-19.



For adult patients shielding at home, the Wellbeing team runs virtual assessments, rehab sessions and support.

In Children's, support for families is delivered virtually, including one-to-one play sessions and Tots 'n' Toys.



A new bereavement service launches, open to anyone who needs it. Just call **0800 035 3011** (9am-5pm, Monday to Friday).



In summer, shielding patients enjoy socially distanced visits from the team dropping off wellbeing gift boxes.



The warmer weather means the Children's team can organise activities in patients' gardens.



At Christmas, our very own Santa's elves were out delivering presents to the children.



Keech volunteers win royal seal of approval

Our work just wouldn't be possible without our volunteers - they are the backbone of our charity. Now all their hard work and commitment has been recognised at the highest level, with The Queen's Award for Voluntary Service.

The award announcement was followed by a 'tweet' from Her Majesty's official account where she said our volunteers were worthy winners of the award. We certainly agree!

Stop/start year for our shops

Having to close our shops for so much of the last 12 months has been a blow - every year, over £1 million of our funding for our care services comes from our 33 charity shops. That said, our supporters made sure there were some fantastic highlights.

- When we were able to take donations again, people rushed to #DeclutterForKeech at both our pop-up 'donation stations' and their local shop.
- In the few weeks our shops were open before Christmas, sales rocketed with socially distanced customers.
- When shops were closed, our customers went online: we set records for our eBay sales. www.keech.org.uk/ebay

All change for fundraising events

With our 2020 fundraisers postponed or cancelled, you - our amazing supporters - stepped up to raise much-needed funds for us.

- You got moving with our sponsored individual fitness challenges to run, walk, cycle or swim.
- You came together as a community - with Tony Dibbin of Absolute 80s and Greatest Hits Radio - for our virtual quizzes and a rocking Facebook KeechFest.
- You bought raffle tickets, signed up for our lottery and gave individually in greater numbers than ever before.
- At Christmas, you donated digitally when Smiley Sam and Bob Sleigh did their rounds with Santa. As many of you said, it wouldn't be Christmas without them!

Thank you for supporting our 'new normal' fundraising. You're making the difference when it matters the most - and we need you now more than ever.



1991

After a massive fundraising effort by a committed and determined Appeal Committee - led by Dr Wink White and his wife Iris - Luton and south Bedfordshire's adult hospice welcomes its first patient. A Royal opening by the Duchess of Gloucester follows in November.

1993

Our first shop opens in Dunstable. Over the years, this has grown to 33 shops across our communities, contributing over £1m a year towards our care.

1996

Adult patients start coming to the hospice for rehab, treatments and therapies, thanks to our new day-support centre. Our Lottery launches and an early version of Smiley Sam goes out for the first time at Christmas.



YEARS OF CARE

2000

The children's service is born, welcomed into the world by HRH The Princess Royal.

2002

The hydrotherapy pool opens with a big splash!

2005

Sparklers support group lightens the load for the children and young siblings of patients.

2007

More local families benefit from our support when we become the children's hospice for Milton Keynes as well as Hertfordshire and Bedfordshire.

2009

Facilities for patients and their families are extended and modernised in the adult in-patient unit; adult and children's services unite to become Keech Hospice Care.



2019

Keech volunteers train to help patients who may lose their voice, with our new voice banking service.

2018

Families of any child with a life-limiting illness now benefit from our new 24-hour adviceline. Local health professionals up-skill with our newly formed clinical education team. Our first-ever aquatic therapist gets patients mobile in the pool.

2017

The focus is on adult patients' mobility and quality of life as we launch the Independence and Wellbeing Service. TV gardener Adam Frost creates our beautiful, contemplative Courtyard Garden.

2016

TRHs The Duke and Duchess of Cambridge visit the hospice to celebrate our 25th birthday.

2015

The first KeechFest celebrates the opening of our Alan Titchmarsh-designed wildlife garden.

2014

Patients and carers can access 24/7 support when the adult helpline launches.

2011

Adult patients benefit from additional services and facilities when the day-support centre transforms into Keech Palliative Care Centre.



2020

Our Wellbeing Centre opens, bringing together everything patients need to live well and be independent. Our volunteers receive the highest accolade: The Queen's Award for Voluntary Service. And we came together in a time of crisis to support patients and their families on the frontline of the coronavirus pandemic.



2021

Our 30th anniversary sees us still on the pandemic frontline, working round the clock, to Keep Keech Caring for another 30 years.



When motor neurone disease is the *'new normal'*



Linda learnt she had this devastating illness just as the world started battling the pandemic. But coronavirus wouldn't stop Keech giving her the care she desperately needed.

In early 2018, my left leg began giving way so I was falling on hills and stairs. Then my right leg started to give me issues followed by my hands and arms - I couldn't unlock my front door, kept dropping things and my left arm refused to cooperate when typing at work. Things got quickly worse - I lost the use of my left hand completely, was experiencing weakness and spasms widely, and only managing 45 minutes sleep at night due to the spasms and intense pain.

Finally, after seeing many specialists and undergoing neurological testing which showed widespread deterioration, **I was given the devastating news it was highly likely I had MND.**

When I heard this, I just put my head in the sand, really battling against it. At this low point, my neurologist put me in touch with Keech Hospice Care.

Keech's step-by-step care

I cannot explain how comforting it was to have Keech's support at that early stage, taking it one step at a time. Liz from Keech's neurological team called within 24 hours then came to see me. After that, she stayed in touch, visiting regularly and checking my range of movement and mobility.

On the day it was confirmed I had MND - via a telephone consultation with a neurological specialist in London, due to the spring lockdown - Liz phoned me afterwards within the hour.

You go through a whole mix of emotions - sad one moment, angry the next - and can't stop thinking about your family. You grieve for the future you're going to miss out on as well as losing your independence: having to ask to go to the toilet, being hoisted from bed to commode to chair, made me feel powerless. **It's like losing "you". You ask, "why me?" and "is this really my life now?"**



“Despite the masks they have to wear, I could always see the Keech team's smiles and compassion.”

Keeping a sense of control

When my condition rapidly worsened and my symptoms became too difficult to control, the Keech neuro team arranged for me to stay at the hospice so I could be observed by doctors, assessed by the occupational therapist, and have help with symptoms, medication and coming to terms with my diagnosis.

I found the hospice to be a place of peace. Looking out at the beautiful, peaceful surroundings in those first 24 hours, knowing I was being cared for by people who were used to patients with a palliative diagnosis, I came to a place of serenity.

You can talk to anyone at Keech about anything. Unlike with friends and family, there's never an elephant in the room. I could talk openly about death and dying, including the practical things that had to be put in place. Talking through my concerns helped me gradually come to terms with my situation.

Due to Covid-19, all the staff had to wear protective gear, including masks, during my stay. **Despite the masks, I could still always see the smiles and compassion** as they work alongside you and assist you with what you're going through.

The Keech care team are vastly experienced and have helped so many people through devastating illnesses but it's always clear when they speak to you, it's as an individual who is going through their own very real situation.

Vital help at home

When I went home, Keech coordinated my care with all the relevant professionals in the community like my GP and neurological consultant, making sure everything was smoothly joined up. I can't emphasise enough how much this helps when you're in a maelstrom of emotion, shock and grief, not knowing which way to turn.

I have a community care package in place, which includes weekly support from Keech's Wellbeing Centre team and the social work team as well as a weekly check-in from Supportive Care. I also have a phone number I can call 24/7 for any worries or when I'm just overwhelmed with my situation.

Keech's care and support has helped me accept what's happening to me, the transition from old me to new me. **It's priceless for anyone in my situation, coping with a devastating disease while trying to carry on with your "new normal" life.**

“**Keech's care and support has helped me accept what's happening to me, the transition from old me to new me. That's priceless.**”

A gift for the future

Thirty years ago, it was a gift in a Will that helped turn the dream of our hospice into a reality. Today, these thoughtful gifts help make sure Keech Hospice Care can keep caring for years to come.

Did you know 1 in 7 of our patients are cared for thanks to thoughtful people who remember the hospice in their Will?

By leaving us a gift in your Will, you're helping ensure we'll always be here to provide our free, specialist care and support to seriously ill adults and children, and their families. You're truly making the difference when it matters the most.

Writing your Will is easier than you might think.

We've teamed up with Bequeathed to provide you with a hassle-free Will-writing service. You can make your Will online from the comfort of your own home, often in less than 30 minutes.

Getting started is easy. Type www.bequeathed.org/p/keech into your browser and you'll be guided step by step through the process.

It's a free service and there's no obligation to include a gift to support our care. But we hope - after providing for loved ones - it's something you might consider. A share of 1% or 2% of your estate can have a huge impact.

If you would like to know more about leaving a gift in your Will to Keech Hospice Care, please contact us on **01582 707940**, email letmehelp@keech.org.uk or visit our website at keech.org.uk/giftsinwills.

A little boy beating the odds every day

Rhys, 4, had 15 operations in the first two years of his life and still has more to come. Brad, Rhys' dad, describes how Keech's support has been vital for the family.

Rhys shouldn't be here right now - we've been told so many times to prepare for the worst - but he's always defied the odds. He's such a happy, friendly, chatty little boy despite everything he's been through. His favourite words are "hiya" and "dada", and he loves watching snooker!

My wife Stacey had excess water during her pregnancy but we didn't worry because Stacey's first pregnancy with Rhys' sister, Cerys, had been the same. But it meant, at the scans, they couldn't take some of Rhys' measurements (including his heart), so we didn't know anything was wrong until Stacey had him.

Heart-wrenching news

When he was just a few days old, we were told he had tetralogy of Fallot - a condition involving four defects of the heart which also affect the lungs - and Noonan syndrome, which also comes with heart defects. He has twists in his bowel, too, which means he's now fed through a tube.



“Rhys has had three open-heart surgeries, the first at just four weeks old - a 16-hour operation on a tiny baby.”

This news was totally heart-wrenching. A complete life-changer.

For the first 11 months of Rhys' life, we were told three times to prepare ourselves for losing him. There was one day when he 'died' five times but they managed to revive him each time. He has also had three open-heart surgeries, the first at just four weeks old - a 16-hour operation on a tiny baby. The surgeons told us he may not survive the operation so we were waiting, worrying and thinking, "He's not going to come back."

But he always did - he turns four this year.

Cerys and Rhys have a really strong bond. Cerys has been with Rhys on really bad days but she only ever sees him as her brother. Once, when he was in hospital, she climbed in his cot with him and he just improved immediately. Not even the care staff could understand how he changed so dramatically.

Keech - a lovely place

When our regular complex-care team recommended we try Keech Hospice Care, we were shocked: you don't naturally think of children and hospices, you think it's somewhere older people go to die. So, at first, the Keech team came to our house to meet us. Then we went to the hospice itself to have a look around and found it was the complete opposite to what most people think a hospice will be like. It's such a lovely place and the staff are just amazing.

After that, Rhys and I went to Tots 'n' Toys, Keech's weekly activities session for under-fives, where we could talk to other families in similar positions. It was such a relief to be able to do this because they understand what other people don't - for example, situations like not knowing if your child is going to make it through when signing a consent form or the difficulties of feeding a child through a tube.

Supporting the whole family

The amount of help we've had from Keech Hospice Care is staggering, whether we're at the hospice or talking to them on the phone. The team has also been able to help Cerys with her anxiety about what's happened to Rhys. Before Covid restrictions, she went to Keech's Sparklers support group for siblings every month - which she loved as she's only eight and has been through so much. She's definitely wise beyond her years but does need support. Sparklers takes her away from the reality of Rhys' condition.

We've also been on Keech-organised days out as a family - including a Christmas panto - and Rhys has stayed over at the hospice so we can spend quality time with Cerys.

The four years since Rhys was born have been an emotional roller coaster that can either break you or make you. I have to say, we've never argued as we know more than anyone what is important in life.

We've been told Rhys won't reach double figures but who knows? As a family, we've got to give him the best life we can for however long he's got. And Rhys is a fighter - he wants to be here.



ARE YOU READY FOR AN EXCITING YEAR?

Amazing events for 2021 guaranteed to put the colour back into your life after lockdown.



THE BIG TRUNK TRAIL

Where: around Luton **When:** 10 July for 13 weeks.

The Big Trunk Trail is the biggest, most unique outdoor public art event Luton's ever seen. Over 30 beautifully decorated elephant sculptures will trumpet along a free, fun, family-friendly trail around Luton.

Keech is bringing the Trail to Luton to celebrate our 30th anniversary and say thank you to everyone who has supported our work over the last 30 years. To keep in touch with all the elephant-tastic goings on, visit www.bigtrunktrail.co.uk



Ultimate challenges for adrenaline junkies!

Fancy falling through the air from 10,000ft? What about standing on top of a plane instead of sitting inside it? Or why not abseil down the UK's highest freetail-abseil building?

Visit www.keech.org/whats-on to find out more.



COLOUR DASH

Where: Luton Regional Recreation Ground
When: Sunday 27 June

When is it OK to start off in a pristine white t-shirt but finish looking like you've walked, jogged or ran through a rainbow? Colour Dash 5K, of course! Sign up for a fun day made for sharing with family and friends.

www.keech.org.uk/colouredash

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INTRODUCING



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SCAN HERE TO
BRING OUR BIG
TRUNK TRAIL
TO LIFE!



Keech is bringing the Trail to Luton for **13 weeks from the 10 July** to celebrate our 30th anniversary and say thank you to everyone who has supported our work over the last 30 years.



#JOINTHEHERD AND KEEP UP TO DATE ON ALL OUR
ELEPHANT-TASTIC GOINGS ON.

f @bigTrunkTrail

www.bigtrunktrail.co.uk