Shine
the Shooting Star Chase magazine

Winter 2015

The value of therapies
Why they are so much more than an added extra

Shooting Star House celebrates 10th birthday
Simon Cowell announced as new Vice President
Kyffin’s, Jordan’s and Alice’s stories

Make every moment count for babies, children and young people with life-limiting conditions, and their families.
Welcome to Shine!

Welcome to the winter edition of Shine, sharing all the great things going on at Shooting Star Chase. Introducing our guest editors, Tamanna, 16, and Sanam, 12.

The Friendlies have asked us to be the very first guest editors of Shine, and nobody says no to Professor Popplepants! We’ve been going to Shooting Star House for ten years with our sister Spud. It’s a great place. When it first opened it felt a bit clinical but it has got better and better. It’s really family friendly and we have so much fun. We love the art room, we play board games and we do loads of stuff in the garden – Spud loves being ball girl when we play tennis outside!

We’re known at the hospice for having a laugh, and making a lot of noise. One time we were in the music room, belting out a big rendition of Bohemian Rhapsody. Mum was on the microphone in full Freddie Mercury mode! We thought the room was completely sound proofed but when we came out everyone was laughing at us because they could hear us everywhere!

Shooting Star House is like a second home for us. We feel really comfortable there, in fact we probably get more comfortable at Shooting Star House than at home!

Anyway, enough about us, there’s a magazine to read! There’s loads in this issue, including news about Shooting Star House’s 10th birthday and the Festival of Music at Christopher’s to stories from families supported by the charity, and an interesting feature on all the therapies that take place. So, get a cup of tea, put your feet up, and start reading!

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Care we have provided in the last six months
Care figures are from April to September 2015. This includes the summer holidays where demand for our service is at its highest.

4,734 hours of Hospice at Home visits
4,682 in Oct 14 to Mar 15

206 families

685 supported families
656 in Oct 14 to Mar 15

1,592 bednights
1,339 in Oct 14 to Mar 15

Shooting Star House is 10!

Shooting Star House marked its 10th birthday in style with a host of activities celebrating the difference our Hampton hospice has made to families.

Our annual Afternoon Tea at the Dorchester and our summer siblings’ day both had a 10th birthday theme before a big party at Shooting Star House in September. Guests at the party included families first to use the service when the hospice opened in 2005 and a number of people influential in its development over the years.

To mark the birthday, Shooting Star Chase also produced a limited edition set of commemorative cards celebrating the hospice’s milestones through the years, such as HRH Prince of Wales officially opening the hospice in 2006, the installation of the Memory Tree in 2008, the Cosmos Therapy Zone extension in 2009 and being awarded an outstanding rating by the Care Quality Commission in 2014.

Shooting Star House was the dream of Kathryn Turner MBE, who set up a charity in 1995 to provide a home-from-home environment offering medical, practical and emotional services free of charge to families in south-west London. The charity was named Shooting Star Trust in recognition of children with life-limiting conditions who, like shooting stars, shine brightly but are gone far too soon.

After seven years raising the £6 million required to build the hospice, and a further three years’ construction, Shooting Star House opened on 5 August 2005. Within four weeks the hospice cared for 26 children. Ten years on, six of those families remain part of our care service. Shooting Star House now cares for around 375 families, of which approximately 125 receive bereavement support.

Tamanna, Guest editor
The party was great! Mum was pretty embarrassing though because she kept following the giant Minion around to get a photo. She loves Minions!
Our new VP has the X factor

We were delighted to announce a new Vice President in May – none other than TV and music mogul Simon Cowell!

Simon accepted our invitation to become Vice President as recognition of a decade of support, which has included donating exclusive auction prizes and attending and speaking at some of the charity’s high profile events. He has also hosted our annual Afternoon Tea at The Dorchester since 2012 and made private visits to the hospices to spend time with families and staff. Simon’s partner Lauren Silverman has also accepted an invitation to become a Patron, after giving significant support since being introduced to our work by Simon.

Simon Cowell says: “It is a huge honour to have been asked to be Vice President. Everyone involved in the charity does an amazing job caring for babies, children and young people with life-limiting conditions as well as supporting their families. I remember the first time I was invited down to a hospice, and I’ve got to be honest, I was dreading it. I pictured just greyness in my mind before I got there, then I walked in to this place, which should be sad but it wasn’t. Instead, it was – and is – a beautiful place to be.

“I’ve formed a very close bond with those involved with the charity and it has become extremely close to my heart. I hope my ongoing role will encourage others to get involved – the support Shooting Star Chase receives really does make a difference to the care they can provide to families who desperately need it.”

Why I love Shooting Star Chase

Debs Green, volunteer speech and language therapist

“It was a privilege to be invited to volunteer my skills as a speech and language therapist in partnership with the wonderful music therapy service at Shooting Star Chase. I love the opportunity I have been given to facilitate communication and Makaton signing with staff and families. Being able to offer time and skills to such an organisation is a real pleasure.”

Procter & Gamble have helped bereaved families leave a lasting memory of their child at Christopher’s through the refurbishment of a remembrance garden.

The leading consumer product company donated £35,000 to Shooting Star Chase, which covered the entire refurbishment. There was still money left over which Procter & Gamble kindly put towards nurse wages! The Mistral Garden is a special place at our Guildford-based hospice where bereaved families can go for tranquillity, reflection and solace. Families had been able to personalise a pebble in memory of their child and place it in the garden’s rill, but over time the rill had become full and the garden was looking tired. Now, thanks to Procter & Gamble the area has been redesigned, landscaped and renovated under the direction of award-winning garden designer, Selina Botham.

The Mistral Garden has been extended and features curved paths, lots of seating, a water feature and swathes of plants, trees and flowers. Bespoke copper sculptured memory trees have been erected, allowing bereaved families to place a personalised, engraved leaf on the tree, while the original pebbles remain a key feature of the garden.

The garden was officially opened in September and Geraldine Sheedy, Head of Care at Christopher’s, said: “It’s fantastic to have such a beautiful new remembrance garden at Christopher’s and we are extremely grateful to Procter & Gamble for their generous donation. The space is so important for the families we care for and this area of the hospice will provide a place of real peace and reflection at an unimaginable time. The copper trees offer the chance to remember a loved one in a really special way, and it’s brilliant to now be able to give every family the chance to do that if they wish.”

A look inside... Hydrotherapy

One of the most popular facilities at Christopher’s and Shooting Star House is the hydrotherapy pool.

Each pool is heated to 34 degrees and provides many physical benefits, such as helping muscle tone and strength, enabling mobility not possible out of water, and can help relieve pain and reduce inflammation in joints. Both pools have remote-controlled hoist systems and some of our carers are trained in managing tracheostomies in the pools to enable a wide range of children and young people to enjoy the service. The emotional benefits are equally important. Many find it difficult to access public swimming pools, so our hydrotherapy pools are a safe space to help families create special memories. A sophisticated light and music system simply adds to the fun.

What the families say: “The pool at Christopher’s is a complete godsend for Liam, as hydrotherapy really helps with some of his symptoms. Plus, going for a swim at the hospice is something else we can all do together, without having to explain to strangers why Liam is ‘different’.”

The Mistral Garden

Selina Botham.

Phoebe, 10, who struggles to communicate suddenly has control over an entire piece of music. It’s particularly special for the families who watch the performance - the parents are always beaming with pride afterwards when they see what their child has achieved.”

Ten years of sweet music

Budding musicians from Shooting Star Chase teamed up with musicians from London’s best orchestras for our 10th annual Festival of Music.

The event, which took place over three days at Christopher’s, adopted a celebration theme to mark the event’s 10th anniversary. Young people enjoyed two days of workshops composing their own piece of music, which culminated in a grand performance at the hospice on the final day in front of proud families and staff.

The Festival of Music is led by musicians who are a regular fixture in London’s top orchestras. Since its launch in 2006, the Festival of Music has been invaluable to families as they get a rare chance to see their children contribute to a professional performance. The event is particularly beneficial for children supported by Shooting Star Chase who have difficulty communicating, as music enables them to express themselves.

Shooting Star Chase’s Music Therapist, Vicki Kammin, said: “The Festival of Music is so important in giving our supported children an experience they may never have had before and it’s fantastic someone

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Sanam, Guest editor

Going in the pool is fun, because she can float in the water which is relaxing for her. It makes her happy, so that makes us happy too. We get the disco lights and sound system going and dance in the water. It’s our very own version of Strictly Come Dancing, but we call it Strictly Under Water
Family story

When Kyffin was born two months prematurely, there was a team of people waiting to take him to NICU (neonatal intensive care unit). It was the start of six months in hospital for Kyffin and parents Richard and Sarah.

“Intensive care was intimidating because he was in this incubator and there were all these wires, constant beeping and equipment – monitors, UV lights, tubes in his nose,” says Sarah. “You could only touch him by putting your hands through a little port and it was two days before I held him properly. The nurses held all the wires and placed Kyffin on me. It was an amazing feeling.”

After a number of failed attempts to step down his level of care, parents Richard and Sarah began to realise he may have long-term complexities.

“He kept having these episodes and you knew they were serious because the nurses didn’t hang around – they were running to bag him with oxygen and whisk him away,” says Richard. “I think that’s when we realised things would be different.”

“It was a conversation with a doctor that really stuck out for me,” adds Sarah. “All I remember were the words ‘concerns unrelated to his prematurity’. I had Kyffin on my chest and just sobbed my eyes out.”

During Kyffin’s six months in hospital, Sarah sat by his bed ten hours a day, while Richard tried to function at work before returning every evening.

“We had one meeting where a neurologist painted the worst-case scenario based on the initial results of a muscle biopsy,” says Sarah. “She said his condition was so rare that she’d had to research it herself, and then proceeded to tell us Kyffin would never walk or talk, never use his hands or be able to sit, and may need to be ventilated. She concluded by saying his long-term prognosis would depend on him making it through the next few months. It was the worst moment of my life.”

Richard says they felt isolated. “We felt on our own because it was difficult to repeat what we’d been told. I remember ringing my family and explaining we’d had a meeting and it wasn’t great news but couldn’t bring myself to actually tell them the detail. It felt like repeating it would be admitting it was true, and it was too painful to do that.”

“Then Shooting Star Chase arrived to mop us up,” says Sarah. “We’d been in hospital for so long and although we had some great people looking after us, the doctors only really talk clinically. The Symptom Care Team from Shooting Star Chase turned up and suddenly they started talking in a different way – talking about what was best for Kyffin as an individual, and what was best for us as a family. I remember them saying, ‘Wherever you are, we’ll be there for you.’ And they have been.”

The devastating diagnosis was discounted when genetic results came back negative, although the long-term prognosis for Kyffin is still unknown. The current diagnosis is a congenital myopathy, type unknown.

“Because of his complexities, caring for Kyffin is exhausting,” says Sarah. “He has medicines four times a day, plus a feeding pump ten hours overnight and six hours during the day. The day is punctuated by preparing meds, doing a flush, putting the food on, taking the food off, doing a flush, doing the meds, doing a flush. Plus he can’t swallow so you can never predict how his secretions are going to be. At night you’re often running up to suction him. You can never really relax.”

Kyffin attends day care once a week and the family also benefit from short breaks.

“I don’t like to imagine what life would be like without Shooting Star Chase,” says Sarah. “Because of his specific needs, nobody else can really look after Kyffin, so our trips to Shooting Star House are very special. They look after him and we can relax, which means we go back to caring for him with our energy restored, and that helps us be better parents for Kyffin. We’ve both gone part-time to care for Kyffin so that day in day care has effectively allowed us to keep our jobs. Kyffin is happy there too. When we see him he’s beaming. He’s so busy playing we almost have to remind him we’re mummy and daddy when we turn up! Day care has really contributed to his development too. He’s much more confident, happy and engaged.”

One of the things which has stood out for Richard and Sarah is the staff at the hospice.

“We met some great nurses in hospital but it wasn’t across the board,” says Richard. “At Shooting Star House it doesn’t feel like they’re employees doing a job. It’s like they’re friends who want to be there to help you.”
The Shooting Star Chase Ball

Stars including Simon Cowell, Lauren Silverman, Tony Hadley and Dame Joan Collins were out in force to show their support for Shooting Star Chase at our annual ball at The Dorchester in London in October.

This year’s event is set to raise around £100,000, mainly thanks to an auction which boasted money-can’t-buy lots including use of a private jet and lunch in France, a VIP screening of the Rugby World Cup Final at London’s Mayfair Hotel, Afternoon Tea with Dame Joan Collins and Julian Clary, four meet and greet tickets to the X Factor final, and an evening with George Clooney!

As part of the evening, guests were treated to a performance by British ventriloquist Paul Zerdin. Karen Sugarman, Director of Fundraising at Shooting Star Chase, said: “As always, I have been overwhelmed by the generosity and support from every one of our guests. The Shooting Star Chase Ball is always such a fabulous night and we are thrilled to raise so much yet again. This will make a significant difference to families whose lives are turned upside-down and need the vital care and support of our hospice service.”

Now in its 11th year, the Shooting Star Chase Ball has raised more than £1 million since its launch in 2004.

The awesome people at Mulberry HQ came to the rescue when Shooting Star Chase suffered the devastating theft of a second-hand Mulberry bag from our Guildford shop in July.

The high-end accessories retailer heard about the crime in the local paper and kindly donated a brand new, double-sided Bayswater bag not available in the shops. The bag was auctioned at the Shooting Star Chase Ball in October and raised £3,000 for our care services.

The stolen Mulberry bag, which was kindly donated in mint condition, was taken from the shop window and would have raised £500 if sold, enough to provide two visits from a Hospice at Home nurse or five bereaved parents’ groups. The heartbreaking incident is our second theft in less than a year, after thieves raided a storage unit and stole two bicycles worth £630.

Denise Stenning, the Shooting Star Chase Guildford shop manager, said: “It’s hard to believe someone would steal goods from a charity shop, let alone items of such significant value and from an organisation like Shooting Star Chase that cares for sick children with life-limiting conditions. But Mulberry were so very kind to send us one of their prestigious bags to make up for the incident. To know it raised so much more than what the original bag was worth is fantastic.”

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“Some children from Shooting Star Chase came along, there was a little girl who was telling me she’d had 19 operations and she was just such a lovely, happy girl – she stole my heart. On the back of that I volunteered to photograph a fashion show London Welsh were doing for the charity and said I’d be more than happy to help at other events if needed.”

Davina has now volunteered behind the camera at 12 events including three Sunrise Walks, two Hospice Bike Rides, two London Marathons and our Stair Climb.

“Photographically I’d say the Stair Climb is the hardest event to shoot as it’s very limited on space and it was blowing a gale at the top. Ride 100 in 2014 in the torrential rain all day was a tough one too – but I still enjoyed it!”

“I love volunteering for Shooting Star Chase. The Challenge Events team are a great team; they always make sure I’m alright and me feel very welcome.”

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News / a day in the life

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A day in the life of a… Volunteer photographer

Gary Regester
Maintenance Team Leader

“On a Sunday most people are not looking forward to going to work on the Monday but I love Mondays – I love the whole week! It’s a very rewarding job; helping out the families and ensuring everything is safe. For the children we like to make the hospice a home from home. I like to think of it as a wonderland, the children come in and there’s the hydrotherapy pool, all the games, the music room – it’s fantastic, and all the people that work here are just brilliant.”

Uncle Bobble says: The Ball was a fantastic evening, like it is every year, and it raised loads of money for our care service. The only downside was being harassed by Simon Cowell all night as he wanted a selfie with me.

Sanam, Guest editor
How could anyone steal from a charity shop? It makes me mad. Very generous of Mulberry to donate a bag though. Thank you Mulberry!

Dazzler says: Dave is a legend – fact. He has taken some brilliant photos at our events, and better still, he always manages to capture my best side.

From 6am starts to standing outside in the pouring rain for hours, nothing can stop volunteer photographer Dave Jackson getting the best images for Shooting Star Chase.

Over the last few years Dave has taken almost 3,500 photos, capturing our event participants as they run, walk, cycle and climb.

“I think my favourite event has to be the Sunrise Walk, especially when it’s sunny. It’s a lovely walk and location and people are always in such a good mood – the fact it’s so early just adds an extra sparkle to it. I normally arrive for 3.45am ready to capture the shots of all the walkers setting off, then I’ll jump on my bike and cycle to Teddington Lock, Canbury Gardens in Kingston – that’s a beautiful point on the route – and then up to Ham Common before getting back to Ham House to capture the finishers coming in.”

Dave first got involved with the charity while working as club photographer at London Welsh RFC.

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Davina McCall
In line with all services at Shooting Star Chase, the weekend away is free for our supported young people, and enables them to be away from their family for a short time to gain some independence.

Pam Parker, a Physiotherapist at Christopher’s, who organised the trip, said: “We’ve been going away for the weekend with our teenagers for six years and Woodlarks is such a fantastic facility. It’s the perfect place for them to have the freedom to be teenagers and experience a bit of independence – some for the first time. The colour paint fight was particularly popular as they all seemed to love throwing the bright powder at the staff! It was also brilliant to see the older teenagers supporting the younger ones in the group and helping them to come out of their shell, even with little things like how to best manoeuvre their wheelchairs down hills.”

Mrs Pinkyrops says: “I’m still drying out from the huge water fight we had. In line with all services at Shooting Star Chase, the weekend away is free for our supported young people, and enables them to be away from their family for a short time to gain some independence.”

Why I love Shooting Star Chase

Kevin Dewey, Trustee

“There is only one reason – the people! In nine years as a trustee, I have only met the most delightful and dedicated people from the families themselves to the nurses, care and support staff, our corporate, trust and celebrity supporters and the loveable, fabulous volunteers.”

A day in the life of a…

Symptom Care Team Leader

Trocie Lewin-Taylor is team leader of Shooting Star Chase’s Symptom Care Team, which is made up of three Clinical Nurse Specialists and a Consultant in Paediatric Palliative Medicine.

They work closely with other teams at Shooting Star Chase and also with hospitals, GPs and community services to provide symptom management for children and young people at end of life or with very complex medical needs.

“For children requiring symptom management, we will coordinate all services involved with their care and take the lead on making decisions around the child’s medicine and care, ensuring the families’ wishes are at the centre of the decision making.”

“We’re also part of the PATCH service (Paediatric Palliative Care Team, Unit Support for Children and Young People). This includes meetings with patients and their families, and liaising with the families’ GP and the community nursing team to ensure all the equipment and medicine they need is available.”

A day in the life / news

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A look inside... Practice Education

As part of our quest to be a centre of excellence in children’s palliative care, the professional and personal development of all our staff is crucial.

Complexity of care and the changing needs of those we serve means our service is constantly evolving. That’s why we provide hundreds of hours of training to our staff every year.

Our Practice Education Team ensure all staff have the right training and support to do their jobs to the highest standard and quality, enabling us to continue to deliver the best possible care to the children and families we support.

Medical advancements mean children are living longer with very complex conditions, so it is vital our Practice Education Team is always on top of the latest developments and procedures.

The team also works with three universities in our area, offering placements and teaching support. This ensures the nurses of tomorrow have a strong understanding of how children’s hospices, helping to build long-term links with other healthcare providers.

What the families say: “I have a lot of faith and trust in the staff here. More than anywhere else I’ve ever been. This is the only place that we feel our child is completely safe and taken care of. Only at home and here have I seen our child be truly happy.”

Professor Popplepants says: “As a Professor I thought I was the academic one at Shooting Star Chase, but there are some seriously clever people in the Practice Education team. They know their stuff and keep everyone up to date!”
Family story

For parents Mike and Natasha,
January 30th 2013 is a day they’ll always remember as the day their world fell apart.

“This was the day we were delivered the devastating news that our 11-month-old daughter, Alice, had a terminal illness,” explains dad, Mike.

Just 21 days later, whilst lying in her parents’ arms in the garden at Shooting Star House, Alice sadly died.

“There are simply no words that can accurately describe the gut-wrenching agony, pain and desolation we feel for our loss. And there are no text books or manuals that describe accurately how bereaved parents can cope with the loss of their child,” continues Mike.

Whilst friends and family will offer platitudes and sympathy, and we were very grateful for their support, we know we could not have got through those dark days without the magnificent Shooting Star Chase team.

Mike and Natasha were overjoyed to welcome Alice into the world in March 2012; a beautiful, healthy baby.

“There was no reason to believe Alice was anything other than ‘normal’. She was a joyous and happy child, filled with wisdom and spirit, who lived her short life to the full. It wasn’t for nothing that we nicknamed her ‘Chuckles’, because she so frequently did. She had a ready smile that lit up rooms as well as brightened lives.”

When Alice was 8 months old she was first admitted to hospital following trouble feeding. Many tests were carried out all with negative results. Things seemed to get back on track, then Alice started developing brain seizures.

Following 79 days in hospital, the diagnosis was finally made and Alice was found to have an aggressive Mitochondrial disorder, an extremely rare genetically inherited metabolic condition, which prevents the body from converting food into energy.

“After the diagnosis we talked through the potential options – it just wasn’t possible for us to take Alice home so the two choices we had were to stay in hospital or to go to a hospice.

“Our initial reaction was horror, desperation that our precious baby could be going to a hospice. Our instant reaction to the word hospice was ‘end of life, where people spend their final moments, away from home, unfamiliar surroundings, a soulless and sad medical environment’. But this view is so very, very wrong. We know now, the decision to go to Shooting Star House was the best decision we could have ever have made for Alice and our family.

Whilst Great Ormond Street was incredible, a wonderful place, it was still a hospital. We had become obsessed by all the numbers on the monitors, despite knowing that Alice’s illness was never going to improve. We just wanted to be a family again in a loving, warm hospital-free environment.

“As her parents, all we wanted was to enjoy being with our precious daughter, and that is precisely what was an offer at Shooting Star Chase. Alice spent her final afternoon in the sun-filled garden at Shooting Star House with us. She was happy and comfortable and passed very peacefully in our arms.”

Alice stayed in the Tranquil Suite, a special bedroom at Shooting Star House, until her funeral.

“After her passing Alice continued to be cared for, which made it possible for us to return home. Despite extreme sadness, we had the comfort of knowing that Alice was being beautifully looked after and we could visit her at any time; this was a massive support for us and allowed us to slowly come to terms with the awful reality of Alice’s passing.

“As parents we’ve seen first-hand the wonderful work Shooting Star Chase do in supporting families. They are inspirational and awe inspiring in their ability to bring joy, comfort and happiness into the lives of those who are less fortunate.”

Mike and Natasha welcomed their son Samuel in 2014.

“There is absolutely no doubt that the team have helped us to continue with our lives. Of course, not a moment goes by when Alice isn’t in our thoughts; there is an intense, deep-rooted and painful sadness which will never go but the professionalism, love, care and attention that we have received from Shooting Star Chase has been a cornerstone in us moving forward.”

Alice's story

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Family story

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We’re fortunate to have genuinely multi-disciplinary teams at both Christopher’s and Shooting Star House. We offer emotional and physical therapies, consisting of creative therapies including music, play and art therapies, pre-bereavement and bereavement counselling, complementary therapies such as reflexology, aromatherapy and body massage, as well as physiotherapy, occupational therapy and social work. Therapies can be accessed by all members of the family and some, such as counselling and complementary therapy, can be offered to anyone who is significantly involved with the family, including grandparents, aunts and uncles.

In addition to all that, we run a number of groups which are key because they give families an opportunity to meet others in a similar situation and share experiences. We have siblings’ days, sensory days, music groups for children staying at the hospices, pamper days for both mums currently using the service and bereaved mums, grandparents’ days, dads’ days, youth groups and a few more! We’re often contacted for advice by other professionals on our group work, so we certainly have a good reputation of leading the way in that area.

The therapies teams also get involved with training staff. For example, our physiotherapists assist care staff with handling, positioning and therapy programmes for the children. As well as training staff, we make sure they are supported too. At both hospices, we have an informal support group where staff can talk about how things are, and that often reflects life at the hospices at the time. After a child dies we have a staff debrief and we offer ad-hoc support too. We are always available if a member of staff needs us to talk something through.

Our social workers are a recent addition to Shooting Star Chase. As well as supporting families with social-work issues, including liaising with statutory agencies, they will be getting involved in some of the group work. Also our occupational therapists may advocate on behalf of a family to a statutory service about housing adaptations or specialist equipment.

It’s also worth saying that some of our services are carried out by qualified volunteers such as complementary therapists and counsellors, and we are extremely grateful for that support.

Shine: Why is it so important that therapies form an integral part of our care service?

Heather: Right from the start of the children’s hospice movement the ethos was to go beyond just a medical approach. The aim is to provide holistic care to the whole family. Research from the Social Policy Unit is clear that parents of disabled or life-limited children need to be physically and emotionally healthy themselves to be able to cope with the amount of care and stress on them and help their child reach their maximum potential. That’s key to what we do.

The difference our work has on families is the best evidence for its impact. Everything changes at diagnosis and the therapies we offer help families to come to terms with the scale of the world they now live in and how to begin to manage it. Diagnosis is a loss in itself because from that moment all the assumptions and expectations – a child’s first day at school, seeing them get married, becoming a grandparent themselves – they’re all shattered.

I see the impact of therapies when I see bereaved families begin adjusting to what I call their ‘new normal’. I don’t talk about moving on – how can you ever accept and move on from the death of your child? The grief will always be there, so it’s about managing that. A different life starts to grow around the grief. Our bereavement support is particularly strong. We are able to offer support for three years after bereavement, and we are flexible in that time frame too, dependent on how a family is coping. A lot of other providers aren’t able to give that level of support for such a long time. I always see the impact when a bereaved child develops at siblings’ days. They gain confidence and understanding, and find ways of coping with their situation. It is heartening seeing them make friends with each other and exploring emotions that can be really confusing.

Shine: How will therapies evolve in the future?

Heather: As with so much of our care service, the future of therapies we can provide relies heavily on fundraising. I’ve seen significant growth in the time I’ve been here. Eleven years ago, we were running one group at Christopher’s and now we have nearly 30 across both sites. That’s amazing really, although at some point we will need to reflect on those to ensure our resources are going into activities which are giving families the most benefit. It’s hard to exactly pinpoint how we will evolve, because we are led by the needs of the families. The reason we’ve got the service we have is because we have responded to the needs of families and that will always be the focus.

“Everything changes at diagnosis and the therapies we offer help families make sense of the world they now live in and how to begin to manage it.”

As therapists, we reflect the wider care service. In recent years we’ve seen more babies and pre-school children coming to us for palliative and end-of-life care. Responding to the needs of those families is likely to be different from what we’ve done in the past, where we’ve been involved with families over a number of years. At the other end of the scale we will be supporting more families where the young person is preparing to leave a child’s hospice service. For those families they have had to come to terms with a diagnosis and the chance their child may not live into adulthood. Now some are having to transfer to adult services. That can be a confusing message, so we will need to support them through transition.

Of course, we also reflect the society we live in. Statutory services are so hard pressed now to provide these therapies, and that may result in greater demand on us.

Shine: What would you like to introduce in the short term?

Heather: We are really keen to develop the fathers’ groups at both sites. Research shows these groups are better attended when they are facilitated by men and that this can aid the upsilling of care staff outside of the therapies team. Feedback from the two dads’ days we have done was very encouraging. I remember one moment with two dads on stepping stones pointing the ceiling of the hallway at Christopher’s. They started talking about when their child was first diagnosed. It sounds very stereotypical but it felt because each had a paintbrush and were looking at the ceiling rather than the other if facilitated that conversation to happen. I’m not sure you would have got that if we’d have sat them in a room and asked them to discuss their child’s condition and how they felt about it. For some of the dads, the support is where they first time they would have heard another man talk about what it’s like to live with a child with a disability or a life-limiting condition. That’s a powerful thing.

Shine: Why is it so important that we have such a comprehensive range of therapies?

Heather: There is a lot to remember! We’re fortunate to have genuinely so much more than an added extra.
When Shooting Star House opened its doors in 2005, first through the door was 5-year-old Jordan Barfoot and her family. Jordan had been diagnosed with a genetic dysmyelinating disorder, a condition where her nervous system would progressively deteriorate, leaving her unable to feed herself, talk and walk.

“At ten weeks we noticed Jordan had a floppy head and initially put it down to a slight delay in getting stronger. So it was a huge shock when we were given the diagnosis a few months later. Hearing your child has a life-limiting condition just knocks you for six – she’s my third child and you just don’t think it will happen to you.

“At 2 and 3 years old she could do things like hold her drink and sit up, but her condition is degenerative so it was heartbreaking seeing her lose all those things as she got older. It was hard adjusting, especially with two other children to care for as well, but when Shooting Star Chase came into our lives things got easier.”

When Jordan was 5 years old the doctor suggested they use their local hospice for support and Tina, like most families hearing about a hospice for the first time, was daunted by the thought.

“I wasn’t sure I was ready for anything like that but the Head of Care, Sandi, and one of the nurses came over to talk to me about their new hospice in Hampton. It didn’t sound like how I expected a hospice to be, so we agreed to give it a go.

“We all stayed on the opening night ten years ago and, as soon as we stepped through the door, it felt like a home-from-home, especially with the family accommodation upstairs. I thought it would be morbid and sad but it wasn’t at all. It was such a happy, fun place and all three of my daughters loved it instantly.”

Tina’s family haven’t looked back since – they receive 12 nights of short breaks a year, regular Hospice at Home visits, therapies such as counselling, access to facilities like the hydrotherapy pool, and invites to the hospice fun days.

“Having a child with a disability is hard work and Jordan’s sisters and I care for her around the clock. Getting a break isn’t easy because you don’t really feel comfortable leaving them in someone else’s care – but with Shooting Star Chase it’s different. The care is amazing so I never worry. The team have built a really close bond with Jordan over the years. They know her personality, her likes and dislikes, and the signs when she’s not right.

“She’s a girly girl and when she stays at the hospice they’ll do things like paint her nails or they’ll use the sensory room, which she adores. They’re always laughing with her too, because she’s got a wicked sense of humour. She loves staying there so much there have been times when she doesn’t want to come home!

“I’m so thankful we decided to go to Shooting Star House that first night. They’ve given us so much support and life without them would have been a struggle. I know 12 nights or a few home visits doesn’t sound like a big deal to some people but for me that time has a big impact on my life. I trust Shooting Star House so much I’ve even been able to go on holiday while Jordan stays at the hospice – and getting a decent break is priceless.”

To donate go to shootingstarchase.org.uk/donate or call 01932 823100
A small selection of the amazing things you’ve done

**Sophie scales Snowdon**
9-year-old Sophie Lumb from Bagshot scaled the heights of Mount Snowdon in memory of an older brother she never met. Andrew spent the last few weeks of his life at Christopher’s before he died in 2005 and, although Sophie never met her brother she never met, Andrew inspired by his nephew Alfie, who receives support at Shooting Star House. Oliver said: “I chose Shooting Star Chase because without the support they provide, his parents would really struggle to care for Alfie in the way he needs. Having done a mini-triathlon previously I realised I’m not a good swimmer, running hurts, but I can cycle ok! Knowing I can help, albeit in a small way, is very comforting.”

**Très bon Oliver**
Oliver Cock raised £6,160 by cycling 300 miles from London to Paris, inspired by his nephew Alfie, who receives support at Shooting Star House. Oliver said: “I chose Shooting Star Chase because without the support they provide, his parents would really struggle to care for Alfie in the way he needs. Having done a mini-triathlon previously I realised I’m not a good swimmer, running hurts, but I can cycle ok! Knowing I can help, albeit in a small way, is very comforting.”

**Lusso’s perfect drive**
Local award-winning luxury developers, Lusso Homes, have been supporters for many years, but have gone one further in 2015 by naming Shooting Star Chase as their charity of the year. They launched the partnership with a Celebrity Golf Day at Wentworth with a host of well-known faces including music star Brian McFadden, patron Philip Glenister and broadcaster John Inverdale who hosted an auction. The day was a huge success, raising £27,000 for our care services.

**Paul Strank raise the roof**
Paul Strank Roofing held another Paul Strank raise the roof event in September, raising £4,500 by rowing 120 miles of The Thames from Richmond to Lechlade in Gloucestershire. The group has been fundraising for charity for ten years and their latest attempt took them back to their roots. “We began by rowing down the Thames for the Shooting Star Trust so it seemed appropriate on our 10th anniversary to do it again, the harder way this time, for such a good cause,” said Old Crinklies member Adrian Yelland.

**Volunteer in our shops**
Can you spare a few hours to help out in one of our fabulous charity shops? You can learn new skills, make friends and have fun. Working alongside the shop managers, our volunteers are key in enabling us to keep our nine shops running. These raise more than £500,000 a year for our care service. We have shops in Ashford, Guildford, Hampton Hill, Shepperton, Teddington, Twickenham, Walton, Whitchurch and Weybridge. To find out more visit shootingstarchase.org.uk/volunteer

**Deck the halls**
The Surrey Life Shooting Star Chase 2015 Carol Concert is taking place on Thursday 17 December and it’s your chance to get festive! Enjoy your favourite carols, guest artists and special musical performances – including the Shooting Star Chase family choir – plus a wine reception with canapes after the concert. The concert takes place at St George’s College Chapel in Addlestone from 7pm, and tickets are available now by calling 01932 823100.

**Free Wills Network**
We’ve teamed up with the National Free Wills Network, a service offering our supporters a chance to have a simple will written or updated free of charge through a network of solicitors across the UK. When you sign up we will send you a pack with a list of the solicitors in your local area to choose from. There is no obligation to include Shooting Star Chase in your will, but if you’d like your support will help families long into the future. For more information call Katie on 01932 823109.

**Our promise to you**
As part of our fantastic community of supporters, it’s important to us that you have a good experience of Shooting Star Chase. We like to keep you updated with our work but want to make sure we communicate in the best way for you. If you’d like to update your contact preferences, please contact our new Supporter Care Services team on 01932 823100 or supportercare@shootingstarchase.org.uk. You can see our full promise to you at shootingstarchase.org.uk/ourpromise

**You could be a winner**
Our lottery gives you the chance to be £1,000 richer and make every moment count for babies, children and young people with life-limiting conditions. Joining our lottery costs just £1 a week, and there are more than 100 prizes up for grabs every week, including the £1,000 star prize. Our lottery aims to raise £345,000 every year, which is crucial in helping keep our care service running. You can join online at shootingstarchase.org.uk/lottery or by calling 01252 728411.

**Ways you can make every moment count**

**Keep your eyes a-peeled**
Look out for 5-year-old Evie, who is featured in our forthcoming Christmas appeal. The Christmas appeal is one of our most crucial sources of fundraising each year and this year it focuses on the benefits of providing one-to-one care. This allows our staff to go beyond caring for a child’s medical needs and get to know what’s really important to them, meaning a child can enjoy their time with us and parents get a much-needed rest physically and emotionally.
Join us on our annual

**Sunrise Walk**

and every step you take will help make every moment count for bereaved families.

Two great routes: 10km and 20km. One beautiful sunrise.

Sunday 5 June 2016
Starts at 4.30am
Ham House, near Richmond

shootingstarchase.org.uk/sunrisewalk

**New for 2016**
Lots of fun things for kids to do along the way!