

Naomi House & Jacksplace

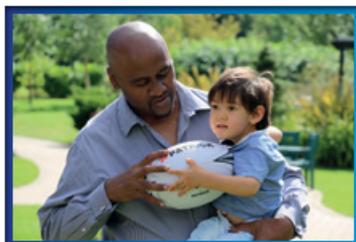
news

SPRING/SUMMER 2016



We're outstanding!

That's the verdict of the Care Quality Commission. [Read more inside...](#)



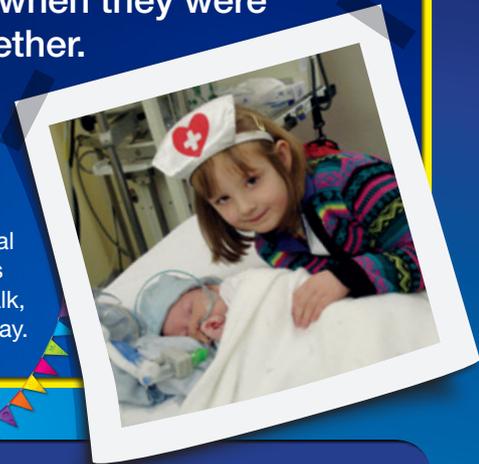
Naomi House & Jacksplace provide respite, emergency, end of life and bereavement care to life-limited and life-threatened children, young people and their families from central southern England.

When families need an extra voice, we're there to help

For Amelia and Bruce, having the support of Naomi House when they were coming to terms with Zack's condition held their family together.

"We had all these unanswered questions, and Liz from Naomi House just pulled it all together and called all of the right people for us. She was someone who would listen and hear what we were saying."

Three year old Zack lives with his mum Amelia, dad Bruce and seven year old sister Isabella in Basingstoke. He was born with a KCNQ2 mutation, which is a rare complex genetic neurological condition which causes Zack to have seizures and generalised dystonia (muscle spasms). He is visually impaired and his development is severely delayed which means he is unable to walk, talk, or feed orally. Zack is fed by a tube and he needs medication every two hours throughout the day.



Amelia told us:

"After a normal pregnancy and birth, we knew quite quickly that Zack was very poorly and he ended up in the Paediatric Intensive Care Unit in Southampton hospital. After lots of tests, we were told his life expectancy was 1 – 2 years based on the type of seizures that he was having. We chose to have Zack christened in hospital. The news was like a thunderbolt. It was a roller coaster of emotions; we were excited about having a new baby and then everything changed in a split second.

"Eventually, after eight months in hospital the doctors said we could take Zack home with a care package in place. Our doctor told us about Naomi House and we were given the choice to go there as part of the transition from hospital to home. We had a few family stays and that really helped us get the confidence with feeding him through his tummy and staff showing us how to give medication. Going to Naomi House with Zack was a break from the hospital environment and a place where we could practise these new skills.

"When we were at home, Zack was still having a lot of seizures and things became complicated. Zack was on a lot of different medicines and we were struggling practically and emotionally. He was in pain and we were having to watch this day in and day out; it was soul destroying. Liz from the Family Support Team at Naomi House came to see us. She helped us deal with all the healthcare professionals involved in Zack's care. Liz is so knowledgeable and experienced, she was able to get hold of the right people and just bring everything together for us. Then things changed for the better for Zack. Sometimes you just need that extra voice. Liz and the team held our family together.

"Zack's dystonia, a result of the KCNQ2 mutation, affects his feeding because of the muscle spasms, he has a peg and has regular medication every two hours throughout the day to stabilise him. As with many of these genetic mutations, every child is unique. Zack had a funduplication operation last year which stops him from being sick. This has improved his quality of life and he has fewer complications when poorly.



He is on a feed throughout the night and 4 pump feeds per day. I am very lucky because I get support from Bruce's mum and my mum, "the nanas" are very involved and supportive. Naomi House in turn supports the whole family, not just the parents and the child. What they do is just amazing.

"When I leave Zack at Naomi House I have mixed emotions and although it feels like something is missing, it is like a weight lifted off my shoulders. We are able to recuperate and do lots of things with Isabella that we can't do with Zack. Isabella is very good with Zack and we are so proud of her. She is always wanting to help, but we are aware of this and don't want her to feel that she is responsible for Zack.

"Zack is on many muscle relaxants so he is not in pain anymore and he is comfortable. That is all we ever wanted. We hope that he continues to be happy and pain free and gets to experience as much as he can, which is what Naomi House and the amazing Treloar Nursery that Zack attends are so good at doing."

Fun Times for Siblings!



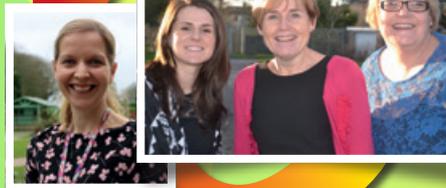
Siblings aged 5-11 yrs took part in a busy and fun day of activities at Naomi House.

The day was themed around what makes them special and was an opportunity for them to meet up with friends they had made at previous sibling days, as well as make some new ones.

Activities included making trophies out of junk to celebrate some of their achievements, and creating their own coats of arms to highlight them and their family. Together they also designed a Naomi House & Jackspace coat of arms, helping them to recognise their link to the hospices.



Expansion of our Community Service



We have launched a new service for families in Wiltshire in partnership with the Jessie May Trust and the Great Western Hospitals NHS Foundation Trust, and have plans to expand our Hampshire service in the near future.

Jacque Scrace, Head of our Community Services, tells us about this important part of our work.

My role as Head of Community Services is an incredibly exciting opportunity to develop a service that reaches out to more families, and offers greater choice and flexibility in the way care is delivered, striving for a service that works seamlessly with other organisations to enable families to access the right care, in the right place, at the right time.

Recent studies have highlighted that although there is an increasing prevalence of children with palliative care needs, a large number of children are yet to access a palliative care service. For many parents, accepting hospice facilities can be incredibly daunting. My role gives me the opportunity to get alongside families and really try to understand what they are scared of, and what it is they need. Offering a service in the family's own home may help to reduce some of

their anxieties and perhaps provide a stepping stone towards enabling a family to feel confident to begin accessing the hospice itself.

We are working in partnership with other organisations to provide regular respite in the home for children and young people who are known to the hospices. In this way, care is delivered by a team of paediatric nurses and carers who are skilled, know the child and family, and have access to a network of support and advice. In addition to our new service in Wiltshire, we have an established partnership with Shooting Star Chase to support children and families in north Hampshire. We aim to expand this community service into more areas to enable all families around the region to have access to Naomi House & Jackspace where and when they need it, but always asking one simple question:

"How can we best support you?"

“We’re outstanding!”

Staff at Naomi House & Jackspace have cause for celebration following a recent visit from the Care Quality Commission's inspectors. In an unannounced two day inspection at the end of last year, a team of inspectors spoke with nursing staff, carers and the family support teams, as well as the children, young people and families cared for at the hospices.

Using a new and more stringent inspection model, the CQC were looking for evidence that the hospices were meeting required standards for quality and suitability of management, caring for people safely and protecting them from harm, treating people with respect and involving them in their care, staffing, and providing care and support that meets people's needs. Naomi House & Jackspace has been given the rating of **“Outstanding”**.

STUNNING PATCHWORK QUILTS



We've been overwhelmed and delighted to receive a number of beautiful handmade patchwork quilts donated by Project Linus.

The quilts were presented by Jane Sloggett, the area co-ordinator and her fellow quilters to our housekeeper Rachel and will help provide a sense of security to babies, children and young people who stay at Naomi House & Jackspace, and will be a source of comfort after a bereavement.

Jane and the team at Project Linus heard about the work of Naomi House & Jackspace through Val Dowd (pictured with her family), who is a dedicated quilter. Val's daughter Catherine was a regular visitor to Naomi House but died in 2014 aged 14. From her personal experience she knew the quilts would be gratefully received at the hospices.

Daisy Trail Cycle Ride



Prompted by the loss of his inspirational wife Emma, Hampshire-based Dave Goodey embarked on a 1500 mile charity cycle ride, leaving a path of daisy seeds in his trail.

Leaving Hvar in Croatia in September 2015, Dave undertook the journey back to Emma's shop, Unique Chique in Alton, Hampshire.

The cycle ride, completed on a tandem with his and Emma's beloved dog Lotte as a constant companion, symbolised the journey he has been on since the death of Emma in 2014 after a long battle with cancer. Dave said, 'I wanted to do something positive after losing Emma, but also something that represented the feelings of loss, loneliness and struggles after bereavement.'

Dave raised a total of over £12,000 split between four charities, Naomi House & Jackspace, Starlight Children's Foundation, NSPCC and Cruse Bereavement Care.

Thank you Dave!



Volunteer Counselling Team



Our Volunteer Counselling Team at Naomi House & Jackspace is hoping to recruit new counsellors to the team this year.

As most people will understand, the loss of a child at any age is devastating. The impact on the family runs deep. Friends and family are often willing to help but often don't know what to do or say.

The Family Support Counselling team at Naomi House & Jackspace offer a confidential and safe space where parents are able to talk about their child and what has happened. The work is challenging and rewarding.

The team comprises qualified volunteer counsellors who are able to spare up to three hours a week. In return we offer

the opportunity to be part of an amazing organisation with training and regular supervision. Most of the sessions are on a one to one basis and take place at the hospices.

We will be holding an open evening at Naomi House & Jackspace in the spring which will offer anyone who is interested the opportunity to come along and speak with our current volunteers and team supervisors.

Please call our **Family Support Team** on **01962 765045** to find out more.



Alastair Stewart's Caterpillar Column

In just two years we have managed to do something pretty special and I am deeply proud to have played a small part in it.

Naomi House first opened in 1997, providing a 'home from home' care environment. However, as families' needs changed, over the years, the hospice needed updating. The work we do there, and the people for whom we do it, is sensitive and vital. I think that helped when our £4 million refurbishment project began in February 2014.

I remember the 'topping out' in December 2014 when Naomi, the daughter of our original benefactor and I waved trowels atop the scaffolding – what a day!

When we 'pushed through' the wall dividing the two new parts of the new Naomi House & Jackspace, in March 2015, I have to admit we had a lot of fun. The children helped and seemed to really enjoy it.

By September last year it was pretty well done, bar a lick of paint here and a few soft-furnishings there. Mikey from Fareham and I did the 'honours' and what a star he was.

The professionalism and love of our staff is a constant. In refurbishing, we weren't only giving a better space to the young people who spend such precious time with us, we were also providing those brilliant professionals with a bigger and better environment in which to do their vital work.

I said then **"We make precious time priceless. We make difficult times bearable. And heartbreak, well, we're there. Loving, flexible and sometimes just silent. But we are there"**.

And we're still there, in better, more modern facilities.

So, job done; and what an honour to have been part of it.

**Alastair Stewart OBE,
Caterpillar Appeal Patron**



Clarendon Way Walk 2016 ...a dad's perspective

"On 5th June I will be walking, then walking. After that I will be walking some more. I won't be doing it alone; at least 1000 others will be ahead, and perhaps alongside. There may even be a few stragglers behind.



We will be 'doing' The Clarendon Way Walk, some of us the whole 26 miles from Winchester to Salisbury, others joining at Broughton. Different ages, different backgrounds, from different places, but with one common goal: to raise money for the amazing place that is Naomi House & Jackspace.

For me it's personal. In April 2013, our precious son and brother, Benjamin, spent his last three weeks at Naomi House. We were all there; Mum and Dad, and Benjamin's sisters, India and Millie. The care and support we all received was, and is, outstanding. In the most desperate of times, far from being alone, we were part of a wider family, helping us to say goodbye. We swam, played, painted, made things and ate - oh, the legendary cakes! We laughed, and of course we cried.

Three years on, Naomi House & Jackspace still offers support to each member of our family. There will always be a Benjamin-shaped hole in our lives, but thanks to Naomi House & Jackspace we don't journey alone.

Will you join me on 5th June?" Dave Taylor

For more information and to register online, visit our website.



Find out more – call us on 01962 760060



Mr Kelloggs makes our day



We are delighted to have struck up a friendship with a wonderful organisation called Pony Pals.

The children and young people at our hospices were visited by an extremely cuddly Palomino miniature horse called Mr Kelloggs. The children had a fabulous time grooming and stroking Mr Kelloggs as he made his way around the hospices introducing himself to everyone he met.



Fitting Tribute to Tiree

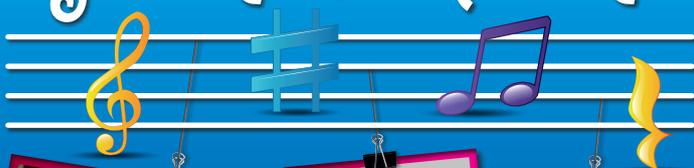


Tiree Nuttall passed away last year having lived with severe epilepsy all of her life. She was a lively young lady who, in spite of her serious medical condition, absolutely loved life and particularly enjoyed her visits to Naomi House & Jackspace.

Tiree received respite care at the hospices, and rested in the Jackspace bereavement suite, Ocean, after her death. Since then, Tiree's parents Janet and Ron from Trowbridge, Wiltshire, have raised a staggering sum of almost £10,000 in Tiree's memory, by organizing discos, auctions and raffles. Players at Trowbridge Rugby Football Club also got in on the action and raised money by wearing bright pink socks during a league match against Reading.

Paul Morgan, Head of Fundraising at Naomi House & Jackspace, commented: **"We are so very grateful to Janet, Ron and their fabulous supporters from Trowbridge and beyond. The money they have raised is enough to pay for 10 bed nights at our hospices and they know better than most how valuable those nights might be to a family facing a situation similar to their own."**

Musical Visit by Ward Thomas



Major British country duo Ward Thomas, delighted children, young people and staff alike when they popped in for a visit to the hospices back in January.

Catherine and Lizzy performed a number of songs for us and were joined by the children on tambourines and bells!



Images - Credit Trevor Porter

Fantastic Serocor!



An impressive £20,000 was raised by the Serocor Group of companies.

Eleven challengers and four support crew covered a gruelling 300 mile route from their Havant HQ to offices in London and Bournemouth via Slough and Oxford.

Taking place over three days the team cycled 100 miles with 7-8 hours in the saddle per day in the 'City Cycle 300' event.

Tom Hickling, Senior Recruitment Consultant, commented, **"As a team and a business we are passionate about supporting charities however we can, so the City Cycle 300 challenge presented an interesting, challenging and fun way to try and make a difference."**



FOAM FILLED FUNDRAISING



Last year's Foam Fest event raised an incredible £30,000! With four more fun filled events this year, we're on course to smash that total – with your help.

With more obstacles and more foam, these are events not to be missed.

Participants will have to dodge, dive, climb and laugh their way through a 3km course of inflatable obstacles, foam pits and cannons.

Sat 23 April
Southsea Common, Portsmouth

Sun 8 May
Baiter Park, Poole, Dorset

Sun 22 May
Prospect Park, Reading

Sun 25 September
Beaulieu, New Forest

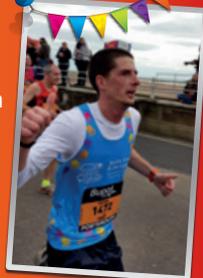
Don't miss the chance to have Foam Filled Fun!
Visit our website to register online.

Be part of Team Naomi & Jack!

If you have your own place in a run why not join our team?

The money you raise will help the vital work of Naomi House & Jackspace supporting children and young people. All runners will have the opportunity to purchase a Naomi House & Jackspace running vest and will receive full support from our fundraising team.

We look forward to hearing from you!



Three Peaks in 24 Hours!



Brace yourself for a fast-paced, physically challenging and memorable adventure as you take on the three highest peaks in England, Scotland and Wales in 24 hours!

Considered to be one of Britain's toughest outdoor challenges, the National 3 Peaks Challenge takes in Ben Nevis (1,344m), Scafell Pike (978m) and Snowdon (1,085m). Grab your team members (minimum 10, maximum of 14) and sign up for a date that suits you! Registration is just £50, with a suggested fundraising target of £550.

Saying goodbye to a friend and fundraiser

Jonah Lomu recently visited Naomi House & Jackspace to meet the children and families we care for.

He also organized a glitzy gala dinner to raise money to help us provide even more care for the region's life-limited and life-threatened children and young adults.

News of Jonah's death shocked and saddened everyone here at Naomi House & Jackspace. His relationship with our

charity was a relatively new one, yet he had a deep understanding of our work and brought many smiles to the faces of children, young people and families cared for at our hospices. He was a tremendous ambassador and a true sporting legend.



He will be greatly missed.

Save the date

Visit our website to find out more about all of our events and to register online.



Caverns Zip Line, Snowdonia

Friday 20th May 2016

Try our brand new challenge and zip down the world's largest fully underground zip line and adventure course!



Clarendon Way Walk

Sunday 5th June 2016

Join us on our 10th birthday celebrations on the 26 mile or 12 mile walk along the Clarendon Way.



Santa Run

Sunday 4th December

Register online now to book your place in this year's 5km run through the streets of Winchester.



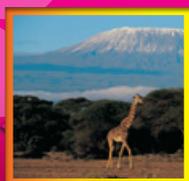
Ultimate Christmas Party

Wednesday 7th December

The glamour of Paris, with entertainers, fabulous dinner, performances, casino and dodgems or simply dance the night away. Join us this year for an unforgettable night with Best Parties Ever!



Special discounted price £40 per person for bookings before 31st August
Standard Price - £46 per person.



Mount Kilimanjaro

23rd September – 2nd October 2016

A six day trek, challenging you both physically and mentally as you climb one of the most impressive mountains in the world, to the summit high above dusty plains and huge glaciers.

Visit our website for information on how to register and to watch "A Brother's Journey", a film shot in October 2015 following a Kilimanjaro adventure.

Buy your own pocket shopper

Now that we have to rethink our use of plastic carrier bags, why not buy a Naomi House & Jacksplace "pocket shopper" which you can keep with you at all times.

Folding away into its own nylon bag, and with a handy clip to attach to the inside of your handbag, at £2.50 it is the perfect solution. Visit our website to buy yours online.



Cardboard Collecting Boxes

Now that the Caterpillar Appeal has drawn to a close, please send in your Caterpillar collecting boxes and you will receive one of our vibrant new collecting boxes in return.

If you have not had one before, tick the box on the enclosed form and we will send one to you. It is perfect for collecting all your loose change!



Thank you to everyone who supports our work and enables us to care for the children and families in our region.

Due to space restrictions, it is not possible to thank every one of our supporters in our newsletter.

All information correct at time of printing, for up to date news and events, please visit our website or call our Supporter Team on 01962 760060.

Cheques should be made payable to Wessex Children's Hospice Trust

Naomi House & Jacksplace
Stockbridge Road, Sutton Scotney, Winchester SO21 3JE

01962 760060

hello@naomihouse.org.uk

www.naomihouse.org.uk

/naomiandjack

@naomiandjack

I would like to donate

Yes, I would like to give a gift of breathing space to families like Zack's.

My donation:

£10 £20 £62 My choice £ _____

My contact details:

Title: _____

First name: _____

Last name: _____

Address: _____

Postcode: _____

Telephone number: _____

Email address: _____

My payment details

I enclose a cheque or postal order payable to Wessex Children's Hospice Trust

Please debit my Visa/MasterCard/CAF Charity Card/Maestro Card with the amount specified

Card number

□ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □

Valid From: Expiry Date: Issue Number: Security Code:

□ □ □ □ □ □ □ □ □ □ □ □ □ □ □ □
Maestro only

Signature: _____ Date: _____

Do you pay tax? If so, by simply completing this form you can increase the value of your gift by 25p for every £1 you have already given.

Make my gift worth even more *giftaid it*

Please tick all boxes you wish to apply:

- I want to Gift Aid my donation today, and any donations
 I have made previously in the past 4 years
 I make in the future

I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.

Signature: _____ Date: _____

If you would like to pay by phone, speak to someone about your donation, or if you would like to become a regular giver please give our Supporter Team a call on 01962 760060 or email us hello@naomihouse.org.uk.

Data Protection: At Naomi House & Jacksplace we care about supporters' privacy. Your details will be held on our database and will not be passed on to any other party (in compliance with the Data Protection Act 1998).

We would like to keep you up to date with our work. Please tick this box if you would like to receive communications from Naomi House & Jacksplace

Thank you so much for your donation. 😊

Please return this slip using the envelope provided to:
Naomi House & Jacksplace, Stockbridge Road, Sutton Scotney,
Winchester, SO21 3JE

Please send me

- Information about becoming a regular giver
 A cardboard collecting box



Give a gift...

...of breathing space to families like Zack's

Naomi House & Jacksplace hospices offer respite care in a homely environment, giving children and young people the opportunity to live their short lives to the full.

Each year we need to raise £7million to run our whole service and deliver our plans and receive less than 10% of our income from statutory sources. We provide care and support 24 hours a day, 365 days a year, free of charge to families like Zack's, but we need your help to do this.

Zack's Mum, Amelia told us:

"To hand Zack over to people we trust is a huge weight off our shoulders, we have some breathing space and leaves us feeling refreshed, giving us the chance to catch up on things that we can't normally do. But we're always so excited to pick Zack up from Naomi House, I walk in and he's always doing something fun and has a smile on his face."



Your generosity helps us offer expert care and support to families like Zack's across the south giving families the confidence and peace of mind they need to enable them to relax and recuperate.

By making a donation you could help us provide:

£10

could buy crafts for a child to make a special gift, creating special memories for their family.

£20

could fund 1 hour of nursing care from a member of our highly trained nursing team.

£62

could fund a multi-sensory session, stimulating the senses of vision, touch, sound and smell.

If you would like to support our work on a regular basis, £10 a month for a year could help pay for a vital hydrotherapy session.

"Zack responds really well to warm water in the hydrotherapy pool, the moment he touches it his body relaxes, he absolutely loves it." Amelia, Zack's Mum



Thank you so much for your support