

Naomi House & Jacksplace

news

Autumn/Winter 2016



Pioneering care in our new Long Term Ventilation Unit

...Easing the move from hospital to home for newly ventilated children and their families.




**Naomi House
& Jacksplace**
hospices for children
and young adults
Registered charity no. 1002832

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

Naomi House is a Lifeline for this Dorset Family

Having the support of Naomi House & Jacksplace helps the Fairclough family to “breathe”.

Suzanne and Neil from Sturminster Newton in Dorset have four children, Archie 17, Hattie 15 and 7 year old twins, Ruby and Finlay. Hattie was diagnosed with the condition hippocampal sclerosis at the age of 14 months. This condition causes Hattie to have very severe and complex epilepsy which has affected her development, speech and mobility.

Because of the severity and regularity of her seizures she needs round the clock, 24 hour care and frequently ends up in intensive care because she has had to be anaesthetised in order to stop her seizures.

Suzanne, Hattie's mum told us:

“The doctors found that part of Hattie's brain wasn't developed properly. The hippocampus is damaged which affects memory retention; this means that she can't learn as quickly as others because she can't retain the information. She will say words that we understand, but at any one time she can only manage about 15 – 20, so if she learns a new word she tends to drop an old one.”

“The main factor of her condition is her epilepsy and her seizures because they are life threatening and we have never been able to control them. She has been on lots of drugs since the age of 10 months when she started having her seizures. The doctors didn't know whether Hattie would live to be an adult as every case is different.”

“Hattie wakes up in the night, and quite often she will have a seizure, so I don't sleep through the night. It's like having a new born baby, you can't really switch off.”

“As well as dealing with Hattie's health problems, as she has got older her behaviour has become more and more challenging.”

“We've been at our wit's end because she's lashing out at people, but the respite at Naomi House is a real break. Even though the whole time we are worried that she is kicking off and hurting somebody or hurting herself, at the same time we know that she is going to be safe. Everything has got to be on Hattie's terms. It is almost as though because she can't communicate very well, her only way of doing it is through aggression or shouting. It's like that is her way of saying, “no I'm not ready to do that and when I am I will let you know.” It's her voice.”



“Naomi House allows us to have quality time with our other children, and also gives us a break. It is constant; you constantly worry, because of the seizures, you worry in case Hattie is going to be aggressive towards anybody else, you worry that she is going to hurt herself. Life is really hard. Some days I'm in floods of tears and other days you just get on with it. It is just how it is.”

“If it wasn't for Naomi House, we wouldn't ever be able to go away. Hattie likes to be at home and she loves what she knows and she loves being at Naomi House. We'll go in and she will plonk herself on one of the sofas and start to take her boots off. Which means she feels really at home.”

“I drop Hattie off, get back in my car and my whole body relaxes. We are a very happy house, it is full, it is loud, but you get to the stage where all the emotions have built up and you are almost suffocating, and then that is taken away when Hattie is on her little holiday at Naomi House. She loves it and I know she is having a good time.”

“Naomi House is a lifeline for us because it just lets us breathe.”

Why music is so important



Music forms a vital part of everything we do here at Naomi House & Jacksplace.

As well as being lots of fun, music also gives the children and young people who can't communicate verbally an opportunity to express themselves, whilst for others it is a chance to have some control over their environment, something which can be lacking in their everyday lives.

A regular visitor to the hospices is Keith Waithe from Essequibo Music. He explained what music means to the young people he works with, and what it means to him in return.

"I learn so much from the young people, and it is my privilege to come here and share my music with them. My approach is very non-traditional and it means that I can change the pace and rhythm of the performance so I am working on a level which works for them. It's great because they become part of the performance and take control."

Peter Brown from the Winnall Rock School visits Naomi House & Jacksplace each week. Winnall Rock School is a charity based in Winchester which helps children and young people make music together by forming bands. Peter uses a variety of approaches during his visits and told us:



"When I meet the children I think how can I best make music with or for them? Should it be gentle or more rocky? Can I encourage their participation with their voice or an instrument? Sometimes we might write music together; be it a love song for a Disney princess or a gothic metal blast. I recently helped one young lady write a song called "Wheelchair Blues", a protest song about when you go out in a wheelchair and places aren't accessible. It's just a matter of thinking, how do we make music for the moment?"

Naomi House & Jacksplace have been awarded the Investors in People Standard!

We employ 171 staff and are supported by 842 volunteers who work at the two hospices in Sutton Scotney near Winchester and across communities in Wiltshire, Dorset, Hampshire, Berkshire, West Sussex, Surrey and the Isle of Wight.

Investors in People is the UK's leading accreditation for business improvement through people management and provides a wealth of resources for businesses to innovate, improve and grow, with a focus on good people making great business.



Awards Aplenty



We are delighted to let you know that Naomi House & Jacksplace has been recognised in a number of local and national awards. Locally, we won the Wilkins Kennedy Award for Excellence in Innovation at the Winchester Business Awards. Our communications team is shortlisted in the

PR Team of the Year category of the Charity Times Awards and we are especially delighted that our fabulous Patron, Alastair Stewart OBE follows in the footsteps of Lenny Henry and Jo Brand after winning for the prestigious Charity Champion Award at the Third Sector Awards.

Having an ACE time with The Tim Henman Foundation

Tennis legend, Tim Henman and his wife Lucy, paid a special visit to our hospices to see for themselves how we offer a unique service for local families on good days, difficult days and last days.

Tim and Lucy were representing The Tim Henman Foundation, a charity which organises programmes to better the lives of disadvantaged young people, focusing on education, health and welfare. The couple were joined by Richard Garrett and Kathryn Hamlet from the Foundation, and spent time touring our state of the art facilities and meeting children and young people who rely on our support.



Not only has The Tim Henman Foundation agreed to help young people in our care achieve greater independence by supporting our Make it Happen Scheme, but Tim also invited a number of young people to attend his recent pro-am doubles tournament at the National Tennis Centre in London.

Kate Mellor has been coming to Naomi House & Jackspace for close to 15 years, and thoroughly enjoyed the day:

"Watching the tennis was so much fun! There was a fantastic mixture of laid back fun and competitiveness that made watching very enjoyable. It was such an amazing experience being able to see these fantastic athletes play up close. Everyone involved in the event was so amazing and welcoming which made the day so enjoyable and relaxing."

Jack's Cabin

Tucked away in the gardens of Jackspace, just behind our wheelchair football pitch and remote control car race track, sits a beautiful new wooden cabin.

Jack's Cabin, as it is called, was built with help from B&Q and the Kier Group and is proving really popular with those cared for at our hospice for young adults. Featuring a television, bar and comfy seating, Jack's Cabin is the perfect place in which to relax with your favourite television show or catch up with friends.

In true Jackspace fashion, the young people officially opened their new space with a lavish Hawaiian themed mocktail party.



New Business Support

We rely on our corporate and business supporters to help raise funds and we are so grateful for the tireless work they do for us.

In order to continue providing the best care possible to children, young people and families we value the opportunity to work with more organisations – not only benefitting Naomi House & Jackspace, but also their business. We can develop a bespoke package of activities which will suit their needs and will assign a dedicated account manager.

John Allen, Managing Director of Redrow Homes Southern Counties Division told us:

“Supporting Naomi House & Jackspace as our nominated charity has allowed Redrow to make a positive contribution to the local community, whilst providing us with excellent team building opportunities via our various fundraising events.”

When chatting with your family, friends and neighbours, why not find out about their place of work and see if they could support us in any way? Please do pass on a contact name to us or ask them to get in touch.



A New Partnership

We are thrilled to announce a new partnership with Countrywide.

Regional Director Mark Holmes from Basingstoke started following us on Twitter and Facebook and was moved enough to climb Mount Kilimanjaro raising £11,000. Inspired by Mark's support, the director of retail for Countrywide, Ian Bonneywell, announced that the whole organisation will now support us as their Charity of the Year 2016/2017 and the partnership was officially launched in January with a black tie event in Southampton.

Ian and Mark visited the hospices to judge a colouring competition that ran throughout June and July attracting 750 entries and raising £1200 towards our messy play. They will now produce more than 60,000 Naomi House & Jackspace branded canvassing cards, for 300 branches to use in their own communities.

Mark began his fundraising with a Charity Football match at Basingstoke Football Club, dress down days, in branch fundraisers, BBQs and opportunities for staff to buy a half day off work for only £5! We are delighted that Countrywide will be continuing Mark's amazing efforts.

Charity of the Year

AECOM are an international engineering design company with offices around the world.



The staff at their Southampton office are supporting Naomi House & Jackspace with a target to raise at least £2,500. They have arranged a variety of fundraising events including a dodgeball tournament, a bikeathon, a 5-a-side football tournament and even office Olympics, involving staff from their Basingstoke office, clients and local companies.

Frances White, Project Surveyor, Project and Cost Management told us:

“Our Southampton office voted to support Naomi House & Jackspace as our chosen charity for 2016. It was a popular choice as most people have families, making it a charity close to the hearts of staff. We have thoroughly enjoyed working with Naomi House & Jackspace and have found the support they have given to be exceptional! It is a great cause and we are proud to support what they do.”

Creating the world's first hospice Long Term Ventilation (LTV) Unit

There are increasing numbers of children and adults who have tracheostomy tubes.

A tracheostomy provides direct access to the trachea through a surgical opening in the neck. Some of these children and adults also require invasive ventilation. This entails attaching the tracheostomy tube to a ventilator that essentially breathes for the child or adult. For children who are tracheostomy ventilated their journey from acute hospital wards to the comfort of their home can be long and challenging.



Newly tracheostomy ventilated children require a care package to be built around their needs. This may include nurses, carers, education providers and physical adjustments to the family home. Everyone involved in a child's care must be trained to deal with their unique set of needs.

The average length of a hospital stay from identification of the need for long term ventilation to discharge is seven to nine months.

During this time, a child will stay in the high dependency unit (HDU), paediatric intensive care or an acute setting within a ward of a major hospital. Family members who wish to visit will encounter the usual challenges when coming to a hospital: finding parking spaces, limited menu options and a lack of private areas. They will be faced by an acute ward, somewhere lacking the warmth and comfort of the family home.

Caring for a newly ventilated child in a hospital setting is extremely expensive, often as much as £1,000 per day.

We believe there is a better way. We have the staff, the skills and will soon have the infrastructure to support our NHS colleagues by providing a better setting in which children can receive care while waiting for their care package. We can give families a caring and supportive environment in which to spend quality time with their child. We can offer a step down from the care given at hospital, and allow parents to take on some of the care for their children, preparing them to provide this care at home with reduced intervention from medical staff.

Our LTV Unit is located above the hospices and will comprise two fully equipped children's bedrooms, an emergency care room for breakdowns in care packages, accommodation for families and communal spaces for play and relaxation. Children and families will also be able to make use of our pool and gardens.

Opening in the spring of 2017, this service will transform the way in which newly ventilated children are cared for, and immediately improve not only their quality of life but that of their family too.

Lisa Leggett shares her memories of her daughter, Lacey, being tracheostomy ventilated

"Lacey returned from theatre looking pale yet rested. We were so scared. What if she hated it? What if she hated us for letting this happen? We sat by Lacey's side and waited for her to wake. She stirred and smiled at us as she opened her big blue eyes. They spoke volumes. She was letting us know we had done the right thing. She was comfortable and I could kiss her beautiful face and see her amazing smile."

"Lacey had to be assessed and a care package agreed. This then went out to tender. The nurses met Lacey and were trained in how to look after her. We wasted four precious months in hospital waiting for this to be put in place. It was distracting and heart-breaking. We were only too aware how precious our time with Lacey was."

"Being in hospital for so long was awful. Accommodation was not always available on the ward. We were run down, tired and stressed. We felt isolated from the world outside. I never left Lacey's side. Dominic and I were like ships that passed in the night. Hospital is a lonely place when you are facing the biggest fight of your life; there's no home cooked food, no comfy sofa, no peace and quiet. It's those little things you miss the most."

"A Long Term Ventilation Unit would have made a huge difference to us. Being able to make that step down from the hospital environment, to spend quality time together and learn how to look after Lacey in a more homely environment would have been so helpful."

Lacey ultimately spent more than nine months in hospital before returning to the family home in Andover. Lacey later received end of life care at Naomi House.

Play therapy

Jenny Astall, Children & Young People's Support Worker, helps us understand the benefits of play therapy.

Adults will often use words to talk about how they are feeling. For children this can be more difficult but they do know how to communicate through play.

At Naomi House & Jacksplace we offer play therapy, an effective form of counselling using creative arts for children, young people and their siblings who access our services.

For some children having a disability can mean that they don't have the same opportunities as their peers to take part in school and social activities. They may feel isolated from their friends and experience low confidence and self-esteem. Siblings may display changes in behaviour following the loss of a brother or sister. Becoming angry, aggressive or withdrawn are not uncommon.

Play therapy can give children the time and space to explore and express themselves and begin to make sense of some of the more challenging aspects of their lives. They might choose to play out thoughts and feelings through the safety of a third person in the form of a puppet, or recreate a difficult situation using the sand tray.

Play therapy can help promote resilience and confidence within the child as well as support the development of healthy relationships, improving their ability to trust themselves and reduce anxiety.

With a generous donation from Spread Some Sunshine charity we have been able to fully equip our Tree House, a dedicated space in the grounds of the hospice. The play therapy toolkit includes dressing up clothes, puppets, arts and crafts, a dolls house, musical instruments and more.

"To play it out is the most natural **self-healing** process in childhood"

*Erik Erickson,
Psychologist*



Hugh Bonneville Visits our hospices!

We were delighted to welcome the much loved actor, Hugh Bonneville and his wife Lulu Williams to the hospices in June.

Hugh had previously narrated a special video for our charity which can be viewed on our website. As an extra treat, Hugh took time out from his busy schedule to spend time with everyone at our hospices. He toured the facilities, stopping for a play in the new sensory room, and had a long chat with our nurses in the living room.

Naomi House & Jacksplace Chief Executive, Mark Smith, said:

We were delighted to welcome both Hugh and Lulu to the hospices to show them our facilities and to meet children, young people and families who rely upon the support of Naomi House & Jacksplace. Everyone was excited to meet them and we're so pleased to have had the opportunity to spend time with them.

Leaving a Legacy

Johnathan had a winning smile.

There was something about him that made everyone around him love him.

Johnathan's mum, Sonia told us:

"He had severe spastic quadriplegic cerebral palsy, he couldn't walk or sit up without help. He couldn't do anything for himself and had to have help with all his day to day needs. He had impaired vision and was unable to communicate verbally, but we understood him and knew when he was happy or needed something."

From the age of 19 Johnathan was a regular visitor to Jacksplace. It was the only place he came to for respite and Sonia knew he enjoyed his visits. He loved being with people and taking part in the trips and activities.

Johnathan died at home from cardio respiratory failure unexpectedly in April 2015 at the age of just 23.

Sonia said:

"Johnathan had so many physical challenges in his life, but he was such a happy person, you couldn't spend any time in his company without laughing, he had the most infectious laugh."

"We wanted Johnathan's legacy to be used to help other young people and families, particularly at Jacksplace because he had such a happy time there. Families benefit so much from all sorts of things at Jacksplace, not just end of life care. Johnathan was such a loving child that had he been able to say something verbally, he would have wanted to help other young people and families in a similar situation, and we were glad to be able to present the cheque."

The generous gift given in Johnathan's memory is enough to pay for a full year of respite at Jacksplace for four young people.

Leaving a legacy to Naomi House & Jacksplace is a very special way to ensure that we can continue to support seriously ill children, young people and their families.

Making a Will gives you peace of mind, knowing that in the event of your death, everyone will know what should happen to your money, possessions and property. It is especially important if you have children or other people who are dependent on you. At the end of October for a fortnight you have the opportunity of making an appointment with a solicitor who will prepare a new Will or update your existing Will, free of charge in return for a donation to Naomi House & Jacksplace.



jack'splace
@naomihouse



Make your Will
Fortnight



31st October -
11th November 2016

See inside for details of the solicitors taking part.



Help us provide care and support to seriously ill children, young people and their families.

A solicitor will prepare a new Will or update your existing Will, free of charge in return for a donation to Naomi House & Jacksplace.

Visit our website for more information and to find a participating solicitor near you.

Remember a loved one

Remember a loved one this Christmas and help support Naomi House & Jacksplace

Join us for either of the very special services in Winchester Cathedral or Christchurch Priory, where you will have the opportunity to remember and celebrate the life of a loved one.



Natalie and Stephen's baby daughter, Brooke, was diagnosed at the age of 6 months with spinal muscular atrophy type 1, a rare genetically inherited neuromuscular condition which is life-limiting. After many months of tests and hospital visits Brooke's health deteriorated. The family were told that she was not responding to treatment and nothing more could be done. Brooke was transferred to Naomi House for her last few precious days where she was cared for surrounded by her family. She died just before her first birthday.

Natalie told us why going to the Light up a Life service is important to her:

"I want to go to the service because even though we have the grave to visit, it is something else we can do to remember Brooke. It is nice that there are lots of people there, so you know that you're not on your own. You know that it has happened to other people, whether it is the same diagnosis or something different, you know you're not alone."

This year we will have two special services:

Winchester Cathedral:
Wednesday 7th December,
7.30pm

Christchurch Priory:
Wednesday 14th December,
7.30pm

You are warmly invited to join us in remembrance and celebration. If you wish to make a dedication and attend either of the services, please contact our Supporter Team. Numbers at the cathedrals will be limited so please contact us as soon as possible to book your place.

Christmas Light up a Life Services

Thursday 1st December – 7pm
Holy Trinity Church, Fareham

Wednesday 7th December – 7pm
St George the Martyr, Waterlooville

Thursday 8th December – 7pm
St Mary's, Old Basing, Basingstoke

Friday 16th December – 7pm
Saint Michael and All Angels Church, Lyndhurst

Tuesday 20th December – 7pm
St Thomas's Church, Salisbury

We look forward to welcoming you and your families at these special Christmas services.



10th Birthday



10th Birthday of our Clarendon Way Walk

Participants taking part in our special 10th birthday walk have collectively raised £215,000 which is the first time in its 10 year history that it has brought in over £200,000!



Keith Wilson, Marketing Manager for Naomi House & Jacksplace, said:

"We are truly delighted by the response to this year's Clarendon Way Walk. The event continues to grow every year and it was just great to see so many people from across the south coming out to support local life-limited and life-threatened children. This year's walk has brought in enough money to pay for a full year of respite care for 13 children which is a terrific result. This will undoubtedly make a massive difference to children, young people and their families."

Karen Flocks - one of our 1400 walkers, said:

"This was the first year I have done this and would like to say the organisation was first class. The army volunteers were fantastic from the start to the finish as well as the other volunteers around the course. Although it was tough in a couple of places, I am ready to sign up next year for such a fantastic cause."

Join us for the 2017 Clarendon Way Walk on June 24th and help beat this year's total!



A challenging climb!



Many congratulations to 11 year old Joe Bass from Sarisbury Green who completed his own Three Peaks Challenge raising a fantastic £363.02.

Joe told us:

"I wanted to climb the three peaks in South Wales because I have been on holiday there and climbed Corn Du and Pen y Fan before but had not climbed Sugar Loaf, although I had tried but the weather stopped me from getting to the top. I knew it was going to be a tough challenge to do in one day but I thought I could raise a lot of money doing it."

"I chose Naomi House & Jacksplace because I was looking for a local charity that helped children and they stood out because of the amazing work they do for life-limited children and young people, also the website was really interesting."

Thank you Joe!

Get Social!

Our newsletter comes out twice a year but you can keep up to date with everything that happens at Naomi House & Jacksplace by following our social media pages

We post daily videos, photos and stories that show just what a huge difference your support is making to the children, young people and families we care for. **Please come and say hi!**

/naomiandjack

@naomiandjack

/naomiandjack

/naomiandjack



Cardboard Collecting Boxes

If you haven't already got one of our eye catching cardboard collecting boxes then give us a call, or pop into your local Naomi House & Jacksplace shop and pick one up. If you would prefer us to send you one, simply tick the box on the attached form and we will put one in the post to you. It's perfect for all your loose change!



Christmas is on its way!



Win a car

Join us for our Reindeer Trail and Christmas Fayre

Saturday 18th December,
10.30am until 4pm

Come and meet Father Christmas at our Reindeer Trail and Christmas Fayre at Swanmore College, Hampshire. Follow the trail and take part in lots of fun activities with your children before meeting the main man himself!

Our Christmas Fayre will have a variety of stalls and stands selling gifts and stocking fillers so you can do some last minute shopping. There will be fundraising games and our popular barbecue and refreshments!



Letter from Santa

We all know that Santa is very busy just before Christmas, but he's never too busy to write a letter to all the special little people in your life!

Just get in touch with us at Naomi House & Jacksplace and for a small donation, we can arrange to have a personalised letter from Santa sent in time for Christmas.

Call our supporter team or visit our website to find out more.

Christmas Bumper Draw

Win a car this Christmas with our big bumper draw!

Beals Estate Agents and Richmond Motor Group have joined forces and donated a car to Naomi House & Jacksplace to be the top prize in our Christmas Bumper Draw. Purchase a raffle ticket for £1 and you could be driving away in a brand new Citroen C1!

Paul Morgan, Head of Fundraising at Naomi House & Jacksplace said:

"Money raised by the lottery is an important source of regular income for our charity and enables the team to develop plans for our services for our children and families that might not otherwise be possible. We are thrilled that Beals and Richmond Motor Group have come together to provide the car that players can win in the 2016 Christmas Draw."

For a chance to win the car as well as other great prizes, all you need to do is attend one of the events organised by Beals and purchase your ticket. Visit our website for more information.

The draw will take place on the 16th December 2016 and the winners will be notified shortly after.



Naomi House & Jacksplace Christmas Party



Book your Christmas party with us and Best Parties Ever and help raise money for Naomi House & Jacksplace!

In association with Best Parties Ever, join us as we enter the shadowy and decadent world of 1890s Paris! Aerial performers will dazzle beneath the Eiffel Tower, street performers will entertain underneath the Arc de Triomphe and the world famous Can Can will get you ready to dance the night away! Later you can enjoy the glamorous casino and jump on the dodgems!



Why not get your friends and colleagues together and book a table? Tickets are £46 per person, including a three course meal and entertainment. Arrival 7pm and carriages at 1.00am.



Find out more – call us on 01962 760060

Save the date



Santa Fun Runs

Southampton, 27th November

Winchester, 4th December

Join the jolliest jog around and sign up for one of our Santa Fun Runs!

Get into the spirit of Christmas and join the 5km Santa Fun Run in Winchester or, new for 2016, we will be bringing our Santa Fun Run to Southampton.

The 2015 Winchester event sold out, so sign up quickly to secure your place at either of these events. Visit our website to register online.



24 Hour Three Peaks Challenge

28th – 30th April 2017

Would you like to join us on our first challenge event of 2017?

The aim is to complete the National Three Peaks Challenge in 24 hours and to raise as much money as possible for Naomi House & Jacksplace! This challenge is tough. It involves reaching the summit of the highest peaks in England, Wales and Scotland and the aim is to do this within 24 hours.

The three peaks are Snowdon, which stands at 1,085m, Scafell Pike at 978m and Ben Nevis at 1,344m. In total, from our start point to back home, we will also be travelling about 1,300 miles, although the 24 hour clock only starts ticking from when we start our first climb and it stops when we have descended our final peak.



Southern India Trek & Community Project

2nd – 12th November 2017

Join us on this fundraising challenge which takes you to breathtakingly beautiful areas of the hill stations of Southern India and offers you a deep cultural insight into the country.

This trek takes you along a route through the highest tea estate in the world; Kolukkumalai, crossing the foothills of the second highest peak in Southern India and through the rolling grassland and natural brooks of the Western Ghats.

You will also spend two days assisting at a project in Trivandrum, which provides assistance to children with cancer and their families. Possible tasks include redecorating and painting, creating a garden and relaxation areas.



Clarendon Way Walk

Sunday 4th June 2017

Salisbury Cathedral to Winchester Cathedral

Join us for the beautiful 26 or 14 mile walk along the Clarendon Way.



Visit our website for the latest information.

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



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