

Naomi House & Jacksplace

news

2017



Progression, passion & professionalism
...shaping the future of hospice care.



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.

Homely Hospice Care



Twins, Callum and Oliver from Newbury in Berkshire, were born in University Hospital Southampton in May 2016.

Sheri and Phil, parents to Callum, Oliver and big sister Amelia, knew as early as the boys' 20 week scan that Callum had hypoplastic left heart syndrome and was going to require medical intervention. Sure enough, Callum required major surgery within five days of birth.

Sheri tells us how their family life was turned upside down:

"It was a surprise to learn we were having twins, but then to find out that one was unwell, you go from thinking about coping with twin boys, to thinking one of them might not even survive! I went through all sorts of emotions. We didn't buy any baby stuff, we just had one of everything because we didn't know what the future would bring.

"After the boys were born we all had to stay in hospital for six months while Callum grew strong enough for his next operation. We were finally allowed home in November and began trying to live a normal life, albeit a normal life with twin boys, one of whom had a nasogastric tube. There were so many unknowns. We just didn't know how life would pan out.

"In October last year we were back in Southampton Hospital and were introduced to Laura Bengree, the clinical nurse specialist who works at Naomi House and the hospital. All we knew about Naomi House was what we had seen on the TV. I didn't know how it would fit into our lives. All I could think about and all I wanted was to go home. That changed when we looked around the hospices and saw the amazing facilities, the lovely swimming pool and everything else.

"We went to Naomi House for the boys' first birthday in May and it was incredible. We just sat out in the sun and had a lovely time as a family. We could relax because there were people there who knew exactly how to look after Callum. You can't necessarily rely on that from friends and family because Callum is so complex.

Children supported in the community = 62



"Once we were there everything slotted into place and nothing else mattered. We had been cooped up in hospital for ages and it was so nice to be out of there. We were even able to invite my Dad and some friends along.

"We came back for our first weekend stay in the middle of June and we got to go swimming. Callum absolutely loved it. It was a really, really nice weekend. It was at that point that we knew we were going home soon, and I knew we were ready because Naomi House had given us the confidence to do it.

"Since then we've been getting care at home from the Naomi House community team and regularly go to the hospices for swimming sessions. The Naomi House pool is the only place we can go swimming together. The community sessions are so helpful, they allow me to go out and get things done while Callum is looked after by someone who knows him and his condition. Having someone to talk to is important because life can be quite lonely.

"People perhaps have a misconception about hospices. I thought it was all about end of life care, but with Naomi House it's about getting the support that you need to live your life. The step down process, from hospital to hospice to home was a huge help to us and we are so glad we did it. It showed us we could manage at home, and here we are."



And now the news with Alastair Stewart OBE

As a father of four, being a Patron of Naomi House & Jackspace is something I am deeply proud of.

I have long been inspired by the wonderful young people who spend precious time with us and by their resilient families. What they face is something all of us would pray never to have to endure. The way they do is a lesson in love and humanity to us all.

Helping them through is the most professional, loving team of people you could hope to meet: from those who manage the charity, to the medical experts at the pounding heart of it all, to the support staff who do so much, they are a joy to behold. So good are our team, that Naomi House & Jackspace have become beacons in this important, sensitive field of work.

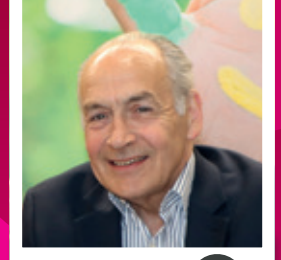
As we approach our 21st anniversary, there is no let up. We will soon open our Long Term Ventilation Unit, giving newly ventilated children somewhere to stay for extended periods while awaiting the creation of their care package.

We are working closer than ever with colleagues in the NHS, particularly University Hospital Southampton, ensuring families receive high quality care and seamless continuity of service.

Our vision is that every child, young adult and their families receive the care services they need, when and where they need them and for as long as needed.

It isn't cheap and we constantly need the support of our many friends to boost the funds at our disposal to help our precious young people and their wonderful families.

But every minute and every pound spent helping Naomi House & Jackspace is worth it.



Pushing boundaries in hospice care

It is our goal to offer care and support to the 500 children and 350 young people with life-limiting and life-threatening conditions in the Wessex region.



This ambition has been made achievable by the appointment of highly skilled senior medical professionals, enhancements to our two hospice buildings and the continued development of our staff skills.

One particular group of children who we are insistent shouldn't be left behind are those requiring peritoneal dialysis. This form of dialysis uses the peritoneum in a child's abdomen as the membrane through which excess water and toxins are passed from the body. Children who require this treatment spend many hours undergoing dialysis each day, often through the night, and this means parents struggle to truly relax.

Now, thanks to extensive training in partnership with the superb renal team and clinical nurse specialist at University Hospital Southampton, we have trained seven Naomi House & Jackspace nurses in the delivery of peritoneal dialysis. We have plans to further extend this training and have even more staff skilled in this element of complex care.

We are increasing our complex care offering to ensure we are there for any child and young person in our region who may need to access our high quality service. Whether the child requires invasive tracheostomy ventilation or complex symptom management at end of life, our teams are skilled and equipped to meet the need.



Staff training per person = £1,800

Jacksplace

The beginning of an adventure.

Jacksplace is a purpose built hospice for young people aged 16–35. We provide quality respite, palliative and end of life care in a home from home environment, where young people have independence, privacy and dignity.

What do the young people say?

Ben told us:

“Whether you are ill or not, at Jacksplace people accept you for who you are. If you are having a rough day, the nurses are there to support you. If you are having a good day, they help you make the most of it.”

27 year old Ben from Alton in Hampshire, lives with his parents, younger brother and pet dog. He has multiple physical disabilities, autism and is a wheelchair user. He started to lose his sight at the age of 12 and by the time he was 16 he was blind.

“Coming to Jacksplace has taught me that despite all the problems that I have and all my daily struggles with pain, there is life after school. Since coming to Jacksplace it has just changed me so much as a person. I am a lot more confident and don't feel frightened like I used to. When I first came I was very scared, but I was told that it was natural and I was constantly reassured by the staff and they really helped me settle down.

“I've learnt from Jacksplace, that it's not the end, **it's just the beginning of an adventure** and fun, and focusses on what you can do and how to make life more comfortable and bearable for you. I am full of admiration for the whole team at Naomi House & Jacksplace and how they look after people. I am just amazed by how much I have come on and so are many other people and I fully put that down to Jacksplace.”

Daryl

“I like going out on trips – to the cinema and bowling.”

Ebony

“It means a lot to me because you get to make your own decisions. Everyone feels anxious at first, but when you come here you feel fine, you feel at home.”

Abi

“At Jacksplace I have the opportunity to be the 24 year old girl I am – late nights (even later mornings), trips to the casino, clubbing etc. I very rarely have these chances at home. Jacksplace has given me my life back.”

Naomi

“I am very excited and intrigued to see what they have planned for the future, I'm sure we'll have more fun times to come!”

Sara – Deputy Play Coordinator

“We talk to the young people to see what they would like to do when they come in, what they are expecting from us and what we can help them do.”



Ben



Daryl



Ebony



Abi, Naomi & Leah

One night of respite = **£1,200**

Young people supported = **92**

Independence

Privacy

Dignity

Follow us on Twitter – @naomiandjack



The importance of play

There's so much more to being a member of the play team than meets the eye.

The team say that 'every child deserves to play but some need to play in a different way', and their biggest challenge is ensuring they cater for all of the children and young people we care for in an appropriate way. Many will have sensory needs, some will be non-verbally communicative, they will encompass a huge array of complex medical needs and some will have behavioural challenges.

Before a child or young person visits, the team will know them well. They will have researched their likes, dislikes, development needs, methods of communication, educational needs and will prepare a range of activities perfectly suited to their individual requirements. The team enable children and young people to take part in activities which will stimulate senses, encourage communication and promote independence. From a session in the sensory room – set up specifically for each child's sensory needs – to arts and craft sessions, trips out ice skating or to the local farm.

Many congratulations to the Play & Activities Team who have been shortlisted in the acclaimed Children & Young People Now Awards 2017.

Huw Bromage, Play & Activities Coordinator, said:

"It is vital we perform our jobs to the very best of our abilities, because that's what those in our care deserve. It is great that the effort of our team is recognised nationally."



Volunteering

Doing something awesome!

Volunteers at Naomi House & Jacksplace bring with them a huge range of skills and experience.

Whether it be tending to our beautiful gardens, out in our shops, at our fundraising events or alongside our care team in the hospices, the time they give is invaluable to the children, young people and families we support.

Serena has been volunteering for seven years and told us:

"I really enjoy volunteering with the play team at Jacksplace; the young people and staff are truly inspirational. They have so many great ideas and make me feel part of the team, welcoming my input too. It's so lovely to help the young people with their activities – there is lots of fun and laughter and when you see them smile it's just wonderful!"

Get in touch...

if you would like to join our team of 875 amazing Volunteers!

Go comms!

Many congratulations to our communications team who have been shortlisted for two major national awards.



They are finalists in the Third Sector Awards, Communications Team of the Year category and the Charity Times PR Team of the Year. The team of three, Keith Wilson, Lynda Barrow and Gemma Brennan work across the charity to raise awareness of the services available to families and demonstrate the impact of the organisation to potential supporters.

Where next for Naomi House & Jacksplace?

Our service is rapidly expanding, and as a progressive and forward-thinking charity, we have ensured our facilities and the skills and competencies of our staff have kept pace with changes in care.

We have a large team of care professionals with extensive knowledge and experience in all aspects of paediatric palliative care, but we always strive to do more. Our intention is to become a recognised Regional Centre for Paediatric Palliative Care.

It is an ambitious and challenging goal but one which the entire team here at Naomi House & Jacksplace is fully behind as we



know we can reach and support even greater numbers of children, young people and families.

There is work to do before we achieve Regional Centre for Paediatric Palliative Care status, not least the recruitment of an additional paediatric palliative care consultant and an increase in the amount of teaching we provide, particularly to palliative care doctors.

Ultimately, we hope that our progressive approach will provide the impetus for the creation of local and national networks of care providers, led by specialist centres such as our own, with the primary care, secondary care and third sector providers operating in complete harmony for the benefit of local families.



Breathing Space

As we prepare to open our Long Term Ventilation (LTV) Unit we take a look at why the unit is needed and the difference it will make to the lives of newly tracheostomy ventilated children and their families.

When a child is invasively ventilated by way of tracheostomy – a tube that accesses the windpipe through a surgical opening in the throat – that child has only just begun their journey. A return to the family home is a long way off and that child faces many months in an acute hospital ward while they await the creation of a suitable care package.

Naomi House & Jacksplace's LTV Unit comprises two beds where newly tracheostomy ventilated children can be cared for over a period of months. During this time, our care team will assist in the training of their care package. Families can stay close by in our well-appointed family accommodation, and

begin the process of learning to care for a child with complex needs. The unit also includes an emergency care room where a child can stay should there be a breakdown in their existing care package.

The new LTV Unit will enable hospice staff to reach out to families with medically vulnerable children earlier in their journey, introducing them to the comprehensive range of services available at the hospice. We can then assist families by bringing healthcare agencies together and allowing the family to gradually adjust to their child's new medical needs in a comfortable and safe environment.

Staff = 160

Working with healthcare providers



Naomi House & Jacksplace is independent of the NHS but cannot operate in isolation. We must ensure our services complement those offered by our colleagues in the health service.

Naomi House & Jacksplace, in partnership with Southampton Children's Hospital (part of University Hospital Southampton NHS Foundation Trust), appointed the region's first consultant in paediatric palliative medicine in 2013. Since then, the joint appointments of a specialist nurse and rotational physiotherapist post continues to put Naomi House & Jacksplace at the centre of the development of the specialist paediatric palliative care service for the region.

This formal partnership, working with the region's specialist children's hospital enables Naomi House & Jacksplace to deliver individualised palliative care to children with the most complex medical needs by ensuring seamless communication and continuity between teams in the NHS and in the hospices. This takes the form of respite care during periods of stability, symptom management and emergency care during periods of deterioration, as well as specialist end of life care.

In addition, the clinical teams at Naomi House & Jacksplace work closely with the district hospitals in the region to ensure that the hospice is able to provide comprehensive support and react quickly to the changing needs of patients and their families.

Physiotherapy is extremely important to the children and young people we care for, particularly those with conditions affecting their muscles and movement. Having a specialist working in rotation at the hospices means children and young people can continue a key part of their ongoing treatment while they and their families enjoy a relaxing respite stay at Naomi House & Jacksplace.

Physiotherapy

Focus



The physiotherapist currently on rotation at Naomi House & Jacksplace is Helen Early. She told us a little about her role and the difference physiotherapy can make to young lives.

"Back when I was a teenager I received physiotherapy at Southampton Hospital and it must have stuck with me, because I ended up going back and becoming a physiotherapist myself. I wanted an active job where I could work with people, so this really fits the bill. I have seven years' experience in physiotherapy, including four years working primarily with children. I absolutely love my job and love spending time here at Naomi House & Jacksplace. There is so much variety in the role. No two children are the same and no two days are the same.

The children here often have conditions that can affect their respiratory, neurological and musculoskeletal systems. They can have limited movement and, as a result, limitations on their independence. Physiotherapy can help to address that, as well as ensure they are in optimum condition to make the most of their stay here at the hospices.

A massive part of my job is coming up with ideas to make physiotherapy fun and engaging. It is great to work with the play team who are never short of ideas on how to turn physio into a game. And of course, the pool is a brilliant facility to assist me in my role. The warm water helps muscles to relax and allow easy stretching. It enables us to get children and young people into positions that are simply not possible out of the water.

I go back to University Hospital Southampton once a week and meet with fellow physiotherapists. They are able to brief me on any children who might be referred to Naomi House & Jacksplace soon, and it means I always have access to a hugely experienced team to bounce ideas off."



Session of hydrotherapy = £350

Businesses get busy for hospice care



Our Corporate partners help raise vital funds to support the work of our hospices.

We are truly grateful for this ongoing support and benefit hugely from opportunities to work with organisations, both large and small. We work together to develop bespoke packages to our mutual benefit and we provide dedicated support for the duration of the partnership.

"We set an ambitious target, formed a charity committee and fired everyone up to raise more than ever. This year we've also honed down our core values – a key strand of which is that we "care". Naomi House & Jacksplace have certainly helped us to bring that to life."

Helen Evans, Projects Coordinator, Vail Williams.

We have recently started a new partnership with Romans Estate Agents. As a growing company they are committed to corporate social responsibility and Naomi House & Jacksplace was nominated as a partner of their Winchester, Chandlers Ford and Basingstoke offices. Their staff are keen to fundraise and support a charity in their local community.

"I am always so proud of our people when they get involved and want to make a difference"

Vanessa Foot, Head of Culture and Community Engagement, Romans.

Basingstoke based BNP Paribas, chose Naomi House & Jacksplace to be their **charity partner** for 2017 and 2018. The team threw themselves into fundraising activities taking part in our Ultimate Store Wars events and Gauntlet Games. They held dress down days and raffles as well as taking a group of bereaved families to a day of tennis at Queens, where Greg Rusedski joined them for breakfast – a real highlight for all the families! The Talent Development Programme Group also partnered with Crown Lift Trucks to deliver their own CSR project which included the Three Peaks Challenge and the BNP Paribas Leasing Solutions family fun day.

We are very grateful to our charity of the year partnerships, we couldn't do what we do without their incredible support and commitment – well done to all involved and thank you!



Bayer

raised over £24,000 from events including their **Reading to Paris cycle challenge**



Glory Global

raised £8,503 at the **charity hustle**



BNP Paribas family fun day



NATS Graduates

raised a grand total of £1,775 in the **Store Wars challenge**

If you know any organisations which may like to partner with us do get in touch.



Make Your Will Fortnight



Each year 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 & Jackspace.

£12,245 raised in 2016 Thank you!

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.

Leaving a Legacy

There is no obligation to include Naomi House & Jackspace in your Will, but leaving a legacy to Naomi House & Jackspace is a very special way of ensuring that we can continue to support seriously ill children, young people and their families.

£1,878,000 was given to Naomi House & Jackspace through legacies in 2016/17.

Solid Foundations



We receive incredible support from charitable trusts and foundations, helping us to fund the cost of our core services, projects and programmes, as well as equipment and capital items.

Without the donations and grants we receive from these organisations it would not be possible for us to provide our vital palliative care and holistic support services.

One such organisation is the Wiltshire based **Odin Charitable Trust**, who have donated an amazing £66,000 over the past 19 years. Most recently they pledged £9,000 to be split over three years to support essential running costs, such as salaries and overheads.

We also work closely with corporate foundations such as the **Openwork Foundation**, who award grants to charities nominated by Zurich staff. Openwork have generously donated grants to the value of £34,000, most recently supporting the work of our play and activity coordinators with a £10,000 donation. Prior to this they helped to fund the creation of our beautiful music room in the newly refurbished Naomi House.

A bicycle made for two!

We've had great fun in the garden this summer with some fantastic new bikes.

Children love to get out and about on a bike, however for many of the children and young people we care for, this is not a possibility due to their medical conditions, or by the limitations placed upon them by their wheelchairs. We are lucky enough to have been supported by **The Toy Trust**, which is the charity arm of the British Toy and Hobby Association. Funds are raised by the association's members and distributed to children's charities.

The Toy Trust gave us the opportunity to apply for £10,220 under their theme for the year, 'Giving the Gift of Play' to fund two adapted bikes.



Good Citizens

We are very fortunate to have been supported by local NCS groups.



National Citizen Service is a Government initiative bringing together young people aged 16-17 during the holidays and typically they follow a four week programme of adventure, discovery and social action. During the social action phase the groups choose a charity to support and plan and put into action volunteering and fundraising activities.

The young people taking part in the NCS scheme are a shining example of what can be achieved by working together. **They have raised nearly £10,000 for us and we look forward to many more years of their support.**

Take on the challenge!



Whether it is taking on a personal challenge, a team-building event with your work colleagues or a physical challenge with a group of friends, there are many ways to test yourself while fundraising for Naomi House & Jacksplace.



"Completing the Three Peaks Challenge was a great experience, I would recommend it to anyone. It was hard work and the toughest thing I have done to date, but completely worth it for such a great cause." Mark Coombs

More than 5,000 amazing people took part in our events raising more than £350,000 for the work of our hospices!

Our events programme would not be possible without the dedicated help of a huge number of volunteers, and we are always looking to add to this great team. If you think you could spare a few hours to assist us at one of our events, **we would love to hear from you.**



Visit our website for more details of the events you can take part in throughout the year.

Evie's story



"Knowing that we've always got that buffer and a bit of chill time really helps, it's our salvation. There is always help for the whole family." Evie's Dad, Simon



Nine year old Evie lives with her dad Simon, mum Caroline and 12 year old sister Isobel.

Evie has a progressive neurological disorder known as Labrune Syndrome (leukoencephalopathy). Due to the complexity of her condition, it has taken a long time for the doctors to be able to give a diagnosis and only recently has it been established that Evie's condition is caused by a faulty gene. Evie is unable to walk and talk and is fed by tube into her stomach.

Simon told us:

"It is good to have a diagnosis but it actually doesn't change anything; we as parents deal with what comes our way. Evie's condition presents similarly to cerebral palsy, but it is progressive and her symptoms will probably deteriorate.

"When she started school, she could walk, talk and she could feed herself but now she is unable to walk. She used to feed herself with finger foods like pasta but she has lost the ability to do that.

"Evie absolutely loves Naomi House. When we left her for the first time we thought, what have we done? Then you

realise she is in a place where there are people who are even better placed to look after her than us! She has so much fun there. There are lots of accessible things to do and she's got constant one to one attention, which she loves. We know that Evie is going to be looked after well and I love going to pick her up because there is a big smile on her face and you know she has had a good time.

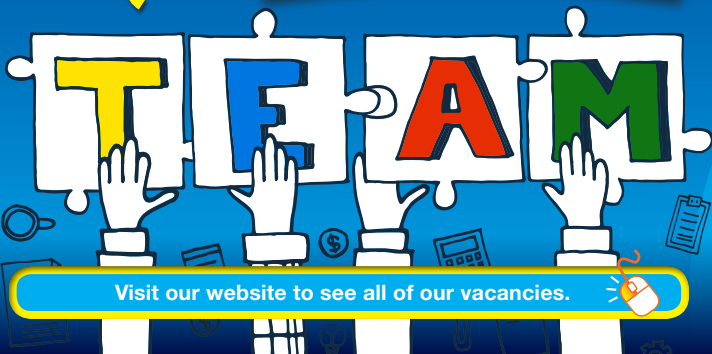
"Evie is full of beans and everything is a laugh. She has such a positive attitude. She doesn't think she's different from the other children, which is lovely. As long as she is involved with the other people and doesn't get left on her own, then she is ok.

"As things deteriorate, you think what is going to be next? We can see the effect it has on people who haven't seen her for a while and it makes us realise that yes, she is getting worse, quickly. We try and shut off that side of things and think, right let's deal with what we've got, otherwise we wouldn't get through the day. You try not to think long term about how it is going to pan out.

"When Evie is staying at Naomi House it just gives us a welcome rest where we can do things with Isobel and be like a 'normal' family for a bit. We know she is in a place where she will be looked after by professionals who are there for your child 24/7 and don't have to go off to do the cooking, don't have to worry about what's in for tea, don't have to worry about another sibling. It eases things for a few days and we can even make a few plans to go out as a couple. It gives us a chance to wind down and 'breathe' for a bit. Sometimes we just need a break for a couple of days just to re-charge the batteries.

"We live day by day. We try not to think too much about the future, we deal with Evie's situation on a day to day basis. Without Naomi House and the dedication of the staff we would not get an opportunity to spend some quality time with our other daughter Isobel and do activities which other families take for granted."

Join the



Visit our website to see all of our vacancies.

Do you know a nurse who could become a member of the Naomi House & Jacksplace team?

It's a hugely diverse role and you simply don't know what each day will bring. Combining excellent clinical skills with a sensitive and compassionate nature, our nurses believe this is quite possibly the most rewarding job in the profession!

Nurse Jenny Tate, told us:

"I haven't worked at Naomi House & Jacksplace for very long but I know coming here was a great choice. Not only will I continue to develop my clinical skills but I have time to be a nurse; to get to know the children, young people and families, and to deliver more in the way of fun, companionship and comfort."

How to help Naomi House & Jacksplace



In 2018 Naomi House & Jacksplace turns 21.
Join in the celebrations!



Visit www.naomihouse.org.uk

Thank you

...to everyone who supports our work and enables us to care for the children, young people and their families across central southern England. We couldn't do this without you.

All information correct at time of printing, for up to date news and events, please visit our website or call our Supporter Services 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

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@ hello@naomihouse.org.uk

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I would like to donate

Yes, I would like to give a gift towards 24/7 care at Naomi House & Jacksplace.

My donation:

£10 £20 £50 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

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

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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 Services 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). More details on how we look after your data can be found on our website.

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



Please support our

24/7 care

At Naomi House & Jacksplace

Respite care gives families the chance to regroup, to relax and to rebalance family life. Naomi House & Jacksplace offer care and support 24 hours a day, 365 days a year, when seriously ill children, young adults and their families need it most, on good days, difficult days and last days.

With the care needs of children and young adults becoming increasingly complex, we are able to offer families a much needed break in a home from home environment, safe in the knowledge that their child will receive high quality professional care delivered with kindness and compassion.

Evie's Dad, Simon, told us:

"When Evie is staying at Naomi House it just gives us a welcome rest and we can be like a 'normal' family for a bit. We know Evie is in a place where she will be looked after by professionals who are there for your child 24/7 and don't have to go off to do the cooking, don't have to worry about what's in for tea and don't have to worry about another sibling."

We would like to ask for your help in achieving our goal of raising £11,600 - the cost of 24 hours of care at Naomi House & Jacksplace.

24 hours of care at Naomi House & Jacksplace can make the world of difference to a family, you can help make this a reality.

Thank you.



We would like to be able to share our news, activities and appeals with you but it is important that we communicate according to your preferences.

Sign me up!

Please tick the boxes that apply.



How would you like us to contact you?

Post Address: _____

Email Address: _____

Phone Number: _____

SMS

Please do not contact me

Thank you so much for your support