

Care and Support ...for good days, difficult days and last days









Faith's Story

"We have no idea how long we have Faith for, so we have to put that to the back of our minds and make every day count. We live life as full as we can for her and for us." Nancy, Faith's mum.





Nancy had a straightforward pregnancy and birth, and baby Faith met all of her developmental milestones. However, Faith had a seizure at the age of five months, the day after her routine immunisations and then a just a few weeks later, she had a second seizure which lasted nearly an hour. It started the cycle of seizures happening every few weeks and was a frightening time for the family.

After months of tests, when Faith was 15 months old, Nancy and Martin were told that she had the rare form of epilepsy, Dravet syndrome, which has a wide range of traits such as autism, ataxia, learning difficulties, speech delay and mobility problems.



Nancy told us:

"We had to get our heads around the fact that the future looked very uncertain for our precious baby. Faith's health became a kind of time bomb. Her seizures can happen at any time - if she is ill or if the temperature changes. If she gets too excited, we have to calm her down. I used to be on call for the fire service, but now it's like being permanently on call.

"Faith loves coming to Naomi House and doing all the different activities; painting, stories, music and the accessible bikes. She is mobile but she also has a wheelchair as she is very wobbly and can't walk very far. She has learning difficulties and her speech is delayed, but she does say a few words. In her own little way, she is very sociable and very affectionate."

To begin with the family, or just Nancy, would accompany Faith to Naomi House, staying in the family accommodation.

"It was great, as I could be with Faith but still have a rest. The first time I went, I had the longest sleep since having her – 12 hours, I couldn't believe it! I thought I would be worried about her and wouldn't be able to sleep, but I slept right through. I woke up in a panic and dressed and went downstairs to see where she was, and she was sat quite happily eating her toast! The carer said, 'Nancy, what are you worried about?'"

Staying at Naomi House has given Nancy and Martin the chance to do some activities just with Faith's little sister Rose, which they hadn't been able to do before.

"Naomi House has allowed us to put a bit of normality back into our lives. Since having their support, we can plan trips and recharge our batteries, which is vital for Rose, as her life is so affected and restricted by Faith's condition. I can also spend time with my husband and not feel like a carer or nurse for a short time.



"Faith loves the kitchen, and the staff and volunteers are amazing with her. She loves going to stand at the counter and watch them. Whenever we go to Naomi House they will put flour on the counter for her, so she can do a bit of messy play and help with pastry making.

Every minute of every day, the team are there for the children. They all communicate with her so well and you can tell that she feels they are her family away from home."

"She is always on the go. She won't sit down and do painting or crafts for hours, or watch a film, so we have to find things to do with her. When it comes to night time at home you don't get a chance to recharge your batteries because she might have a seizure. We know we have to maintain our physical and emotional strength, if I go down we all go down. As parents we have to be on top form.

"It is very hard work, but I wouldn't have it any other way. She is worth everything. Faith has got a lovely personality. She is loving and she makes my job as a mum easy, apart from the medical side of things – that's not easy at all. If she has a seizure and is drugged up, she comes round and looks at me and says 'kisses'. That's all you need, that's why we do it, to get that look, or a cuddle, or a little head butt, that's her way of giving you a kiss."

"I'm so glad we asked Naomi House for their support as it has helped us as a family so much and brought so much joy into Faith and Rose's lives. It's such a happy place and everything is geared towards creating the best experiences for our child whilst in their care."

Visit our website to read the full story.



Miefer Sutherland makes a surprise Visit!



The Hollywood legend was fresh from a performance in Bournemouth and due to play at Wickham Festival, but found enough time to visit the children, young adults, families, nurses and carers at our hospices in Winchester.

He was responding to a plea the charity made on social media, asking Mr Sutherland to pay them a visit for "some tea, cake and a jam". And that's precisely what he did; playing a whole medley of his songs with the support of his band, then enjoying a well-earned cup of tea and some sponge cake while families explained the vital care available to them at the hospices, and staff detailed their complex nursing and care service.

Kiefer stayed for more than an hour before rushing back to the Wickham Festival to deliver a storming set from the main stage.





Neonatal Care

A life may last just for a moment, but that moment can last a lifetime in our memories.



At Naomi House & Jacksplace we provide a range of care to support children, young adults and their families from birth through to the end of life. Now, with the expansion of our neonatal service, we will be able to offer even more care and support to very young babies and their families.

Neonatal care specifically refers to children within the first 28 days of life, and often includes those born prematurely.

Following the appointment of a Neonatal Nurse Specialist, we can reach families who could benefit from our care much earlier in their journey, meaning we are there for families throughout the pregnancy, birth and beyond.

This will enable us to help families with seriously ill children make the most of their precious time together, and ensure plans are in place for the care of the child after birth. Tragically, in many cases, the child we are caring for may only have a few brief moments of life before parents have to say their goodbyes.

Our Neonatal Nurse, Lisa Leppard, works with families throughout their pregnancy. After the birth, the baby and family can come to Naomi House where we assist in the baby's care and in making memories, such as making hand or foot prints or something as simple as going for a family walk.

When a baby dies, they can stay at the hospice surrounded by loved ones while we provide assistance with practical arrangements around the funeral and registration of death, and offer ongoing bereavement and sibling support.







Our Neonatal Nurse Specialist, Lisa, told us:

"It is all about giving families options. When a child is diagnosed with a serious medical condition before birth, they assume their only choice is to opt for a termination. Our neonatal service allows families to carry a baby to term, if that is their choice, and spend time together after that child's birth. All too often that time is extremely limited, but being able to cuddle, read stories or take some family photos together in a non-clinical and supportive environment is surely an option that should be available to families at such a difficult time."



All human relationships are fluid, except perhaps the relationship between a mother or father and their recently deceased child. This is a moment frozen in time, one of unthinkable grief and sadness, but one where a child's very existence can be made permanent despite their death. This is where memory making comes in.



Hector's Story

Lisa supports many families, and Adam and Jessica Roach shared with us how she helped them.

When Jessica was 13 weeks pregnant, the couple found out that their baby had trisomy 18 (also known as Edwards syndrome). Trisomy 18 is a genetic disorder caused by the presence of an extra 18th chromosome. 90-95% of babies born in the UK don't survive to term and only 10% will reach their first birthday.

Jessica and Adam decided they wanted the opportunity to see their baby alive. Lisa supported the family throughout their pregnancy to carry their baby to term and spend time with him after he was born.

"Lisa was a breath of fresh air and positivity in an otherwise feeling of pure gut wrenching sadness. She gave us extra hope and made the whole thing seem bearable. She treated the symptoms, not the syndrome, which was hugely important to us as we wanted the opportunity to see our baby alive. We knew we'd have to bury our child and say goodbye at some stage, but we wanted the chance to see him alive."

Baby Hector was born 10 weeks early via C-section on 2 October 2018.

"Because our time was short with Hector we didn't want to put him through the pain and suffering of incubation. We wanted him to feel love and comfort and we wanted to feel close to him. With the support of the nurses, we held him and had skin to skin time. Then, when we laid him down on Jessica's chest, he opened his eyes. It was amazing. It was so special to be able to look into his eyes."

At just 3 hours old, Hector passed away in the comforting arms of his mum and dad.

"Thanks to Lisa and Naomi House, we were able to take our little boy home for a night. Then, the following day, Lisa arranged for us to go to the Butterfly room at Naomi House.

"From the moment we got to Naomi House we felt we were joining another loving family. It felt like Hector was at home. He was in the next best place than our arms."







Visit our website to watch Hector's inspirational family story.

When a child is resting in Butterfly or Ocean, Naomi House & Jacksplace's post-bereavement care spaces, every family will be given the opportunity to make an item to help remember their child.

After a child dies, Naomi House & Jacksplace's care team will help the family to take locks of hair, hand prints, footprints and fingerprints, some of which can then be turned into jewellery, cufflinks or ornaments. When taking fingerprints of really small children, families may choose a finger that holds special meaning, such as the one used to grip daddy's hand in hospital.

Head of Family Support at Naomi House & Jacksplace, Sue Wilkins, said:

"Memory making is so important. It gives families a tangible and lasting connection with their child. The item they make is like a transitional object; something concrete that will always be there to complement their memories."

Chaplain, Rev. Andy Edmeads, added:

"Believe it or not, families really fear they will forget their child. They won't, of course, but memory making ensures that while the physical signs of that child's life may diminish, part of them will always be with you. It is increasingly common for families to have children's names or hand prints tattooed on their body, and I find this incredibly profound."

At Naomi House & Jacksplace we help families to make positive memories. We hope it is these positive memories that return to a family when they run their fingers over the contours of their child's fingerprint or hold a lock of their hair in their hands.

We offer respite, community, emergency end of life and post bereavement care to 600 families each year









Lucy Hudson lives in Kent but travels to Jacksplace to enjoy respite at the dedicated hospice for young adults.

Lucy says:

"It can be very difficult living with a complex disability, especially when you have a big family. It requires your parents to dedicate a lot of their time to your needs, as well as trying to support your other siblings.

Family life is disrupted by the comings and goings of your carers and it can be quite stressful all round.

This is why respite services are so important.

"I am the oldest of five siblings... but I also have congenital muscular dystrophy as well as other complex needs. For years we've supported each other as best we could; we didn't know any different so it's been normal for us. Yes, it's been difficult at times but we've always found our own ways of dealing with things and done everything as a family. Then, one day, when I was around 12 years old, we were told about respite services and how they not only give families a rest from the daily worries and stresses of caring for a child with a disability, but they also give those with disabilities the chance to have a mini break of their own!

"This is completely different to what I'd always envisaged respite to be. Three or four times a year I would go to the children's respite place, having lots of fun away from my family, in the knowledge that they were also having a well deserved break from my care and that I was being well looked after.

"Where I come from, there are little to no respite facilities, beyond the age of 19 where my complex needs can be properly met and so the first time I visited Jacksplace for respite I travelled approximately 125 miles! Was it worth it? Most definitely!

"Jacksplace means I can experience freedom and independence. It has become my new home from home!"

Home from Home

by Lucy Hudsor

A place of rest, a place of peace,

A place to seek cathartic release.

What this means to you, you will shortly see,

Is not quite the same as it means to me.

I say the word "hospice" and you begin crying,

As, for a short moment, you fear that I'm dying.

But here is the truth, take note, I implore, The role of a hospice is so much more...

To nurture, to teach, to give life more meaning,

As we experience life without parents intervening!

A chance to explore who we want to be,

And learning to live independently.

A place of friendship, a place of fun,

A place where weakness and strength become one.

A place to flourish, a place to grow,

But also a place for when it's time to let go.

Though sad times may arise, when we lose someone dear,

We're safe in the knowledge that they're always here

For families and friends seeking comfort and care;

That special bond we'll always share.

So, dear readers, please understand,

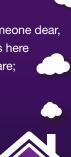
That the sorrows and joys go hand-in-hand,

And, now that I've found them,

I no longer feel alone

In my favourite little getaway...

My Home from Home.



ULTIMATE CLARENDON

26 MILE DUSK TO DAWN OR 52 MILE NIGHT AND DAY

Our annual 26 mile Clarendon Way Walk now has an additional challenge option, taking the brave hearted to another level! We have introduced a 52 mile ultra-challenge, walking through both the night and the day!

Our regular 26 mile walk takes place from Winchester to Salisbury every year on the first Sunday in June and raises over £100,000 each year towards the vital work of Naomi House & Jacksplace.

David Rustell has taken part in the Clarendon Way Walk every year since 2015. He takes his training very seriously and in preparation, has climbed Snowdon and completed the National Three Peaks challenge. David loves to push himself and has now signed up to do the 52 mile Ultimate Clarendon! The walk starts on Saturday night in Salisbury city centre and walkers will reach Winchester in the early morning as the sun is rising. After a rest, the trek back to Salisbury begins with stunning views along the way.



David feels passionately about raising money for Naomi House & Jacksplace, after he and his family were supported by the hospices when their daughter, Heidi, died at the age of just 10.

David told us:

"I've signed up for the full 52 miles and I am trying to recruit all manner of people to meet up with me at varying points throughout the walk, and to raise as much money as possible. I feel this is just a small token of our ongoing appreciation for such an amazing charity, as well as doing our best to make Heidi proud of our efforts. Naomi House has spurred me on. It's all about raising money but it's also got me out doing walks - I love walking now, so everyone's a winner!"



Visit our website for more details and to register.



Three cheers for our volunteers



We have more than 560 hardworking and dedicated volunteers at Naomi House & Jacksplace, volunteering in the hospices, in our shops or at various fundraising events. With fewer than 200 paid staff, we rely on the fantastic support of our volunteers to run a high quality service.

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Volunteers' Week was the perfect opportunity to thank our volunteers at a series of celebratory events. We held an afternoon tea, where volunteers enjoyed homemade cake alongside live musical entertainment from local ukulele band, Sylvi and the Shedettes. The atmosphere was buzzing, with everyone chatting and reminiscing about their personal volunteering journeys

The second event was an informal lunch for our shop volunteers, which featured live music from jazz band, Saxophony and a tour of the hospices, giving guests the chance to see how their shop's income directly benefits the hospices.

We couldn't do what we do without our brilliant volunteers so, a huge thank you to you all!

If you're interested in volunteering for Naomi House & Jacksplace do get in touch.



Sensory Play

At Naomi House & Jacksplace, we provide specialist care for children and young adults with a wide range of complex life limiting and life threatening conditions.

Part of that specialist care is implementing play experiences which include different types of sensory activities

Every child has the right to play, but some may need to play in a different way. Sensory activities consist of a variety of fun and interactive pieces of equipment which engage children by incorporating the five senses. These can include lights and patterns, tactile objects of different shapes and sizes, different sounds, smells, touches and tastes. Children love to play and they do this by using their senses to explore the world around them. This is why sensory activities are so important, to engage and focus the child, so they can have that element of control in their lives as well as having fun whilst doing it.

The sensory room offers another unique experience with a variety of lights, sounds, smells and touch. Children have the ability to change the whole dynamic of the room by making a slight noise with our sound activator switch or a light touch with our touch pads. This gives them that element of control, enabling them to take the activity at their own pace and to do what they want to do in that moment; something that they may not be able to do in their day to day lives.

Sensory activities also consist of small and subtle interactions. A small foil space blanket whilst a child is stretched out on the floor, creates a huge number of sensory connections from the reflections of light, to the feel of it and the sound it makes when it is crumpled into a ball. Sensory activities can benefit a child's communication, confidence and focus. Engaging them in activities which link the senses of sound and touch with everyday object can have a positive outcome on the child's or young adult's development.

All of these activities form a natural play cycle for the child or young adult, helping them explore the environment around them, giving many therapeutic benefits.









We employ 175 brilliant people



Hydrotherapy Sensory Makeover



The refurbishment of our much-loved hydrotherapy pool was made possible with the support of Southern Water, Sun Life Financial of Canada and Vail Williams, who together provided the sum of £28,000 for the equipment and labour.

The pool now features colour mixing lights on the ceilings, which can be changed with floating buttons in the pool, LED Pixel strips, which continue into the changing rooms to provide a relaxing, sensory experience before and after children are in the pool; a mirror ball; music speakers; sensory bubble screens and image projectors, which project animals and shapes onto the walls.

Hydrotherapy is hugely beneficial to the children and young adults at Naomi House & Jacksplace. It allows children to gain a sense of freedom if they're usually wheelchair bound, it soothes muscle pain, stretches limbs and promotes a sense of wellbeing. Being able to combine this with moving lights, music and colours makes the pool the ideal sensory environment. The ability to change and move the colours gives children a sense of control, which is hugely important, as many life limited children and young adults don't have that in their everyday lives.

Beverley Thompson, Community Engagement manager for Southern Water said:

"We have been thrilled to support Naomi House & Jacksplace in their work to transform the hydrotherapy pool. The changes are fantastic and we hope the new pool will provide a fun and interactive space for the children and their families to enjoy."

Matthew Samuel-Camps, Managing Partner at Vail Williams, added:

"We are delighted that the money raised from the fundraising efforts of

our staff for our charity of the year has been put to such good use, providing a much needed resource for the children of Naomi House & Jacksplace. Seeing, in practice, how this money has been invested, is incredibly satisfying and we hope that the children and young adults who use it, reap a great deal of joy and comfort from this fantastic new resource."

A session of hydrotherapy costs £350. This session could allow a child or young adult the chance to swim for the first time, the opportunity to cuddle mum or dad with freedom of movement in the pool, or some essential physiotherapy.

We would like to say a massive thank you to Southern Water, Sun Life Financial of Canada and Vail Williams for their incredibly generous donations. The hydrotherapy pool is a firm favourite and our children and young adults absolutely love it!

Love Coshop Los Shop

Did you know our shops sell more than 13,000 items every week?

We spoke to our Retail Area Manager, Simon Owen, about why shops are so popular.

"Well, first and foremost, customer service is key. We ensure our shops are well laid out, clean, tidy and with friendly and knowledgeable staff on hand to help.

"But that counts for little if the shop doesn't have great stuff to sell. We receive fantastic support from the communities around each shop. Last week alone more than 1,800 bags of stock were donated. We receive really good quality, unique items, and this means we have a great range available for shoppers looking for a bargain.

"Our shops all stock a variety of items but some become known for certain things. Newbury and Winchester are great for fashion, Cosham for vintage items, Andover and Salisbury have an exceptional range of toys and games, Totton and North End are packed with homeware items. We are finding lots of our shops are becoming the local destination for retro gaming consoles, vinyl, 1970's board games and vintage fashion."

Both shoppers and donors help us provide hundreds of hours of high quality care each year. If you haven't visited your local shop yet, why not pay them a visit soon?

€300,000 of care thanks to Byanair

Four years of incredible support, passionate and committed crew, and wonderfully generous passengers, has enabled Europe's number one low cost airline, Ryanair, to donate €300,000 to support seriously ill children and young adults across southern England.

Ryanair's most recent donation of €100,000 was enough to cover the cost of 2,850 hours of high quality nursing care at our hospices. Over the years, Ryanair's donations have provided Naomi House & Jacksplace with enough income to deliver ongoing bereavement support to 100 extended families.

Ryanair scratch cards offer customers the opportunity to win cash prizes, luxury cars and the chance to scoop an impressive €1 million – all for a stake of just €2.



The Great Escape

One of our fantastic supporters, 'The Escape', a brand and digital agency, set off on a mammoth 20k walk from their office in Hatch Warren, Basingstoke, to our hospices in Sutton Scotney. The group of 15, which was made up of eight Escapees, friends and two keen pooches, set off at 09:30 and with plenty of water and food stops, made it to the hospices at 16:00. What was astonishing was the sheer amount of planning that went into making this day a success, deservedly raising a fantastic £1,600!

The Escape were celebrating their 20th birthday at the same time as Naomi House & Jacksplace were celebrating their 21st birthday, so they wanted to celebrate with the charity by undertaking numerous fundraising activities in support. We have very much appreciated their support and look forward to continuing the relationship.



HMS Prince of Wales to support Naomi House & Jacksplace



The newest of the Royal Navy's Queen Elizabethclass aircraft carriers, HMS Prince of Wales, will support Naomi House & Jacksplace for the life of the ship.

The Ship's Company of the 65,000 tonne vessel have affirmed a Bond of Friendship with our hospices, meaning current and future ship's companies will commit to supporting the most seriously ill children and young adults across southern England. The Senior Rates of HMS Prince of Wales have already provided significant support to the charity and visited the hospices.

HMS Prince of Wales is expected to remain in service for up to 50 years and will be home to some 1,600 crew members. With the ship nearing the end of its build phase in Rosyth, it is expected she will take to sea in 2019 before making her home at HM Naval Base Portsmouth.

Our teams have visited HMS Prince of Wales at various stages of her construction.

Ollie's Story

"Ollie is very, very cheeky.

He loves people and loves life. He smiles constantly and delights in making other people smile. He is mischievous and just finds joy in life." Vickey, Ollie's mum

Seven year old Ollie has the very rare condition, Alternating Hemiplegia of Childhood (AHC), meaning any muscle in his body can become paralysed at any time, including his heart and his lungs. This affects his breathing, so he can stop breathing at any time, it affects his swallowing, so he is fed through a tube, and affects his arms, legs and entire body, so he cannot stand or walk. Ollie lives with his mum, Vickey, dad, Adrian, and little sister, Lisi, in Southampton.



"Ollie was born under emergency caesarean and, at just 20 hours old, had to have surgery. It was probably one of the most difficult times of my life, having to be separated from my baby, it was really tough. He was on a ventilator for about 36 hours, but true to Ollie's form and determination, he actually managed to leave hospital within seven days. He left with strange breathing but it wasn't affecting him so we were allowed to leave. We were told to just get on with life, with follow up appointments, and they thought he would outgrow the problems.'

Within a few months, baby Ollie started having hemiplegia (paralysis on one side of his body), then when he was around a year old it became much worse and he ended up in hospital for over three weeks. His breathing had also got worse and had to undergo many rounds of tests. Ollie was finally diagnosed at the age of 2 1/2, around the time that Lisi was born.

"Ollie's breathing difficulties happen at night time as well as during the day, so whenever he does sleep, I'm in an absolute panic. We never fully rest as we always need to listen out for him and make sure he's ok. Every morning when we wake up, we don't know whether he's going to be alive or not when we walk into his room. I always send Adrian in first because I can't face the idea that I might walk in and he might not be alive.

"On our first stay at Naomi House, I was trying to work out what I needed to pack and worrying about whether I had all the right medication and feeds. But when I walked in, there was just a sense of relief and a sense of fun. We were able to walk away at tea time, knowing that the nurses would put Ollie to bed. We were able to give Lisi, for probably the first time ever, time just for her and Adrian and me, and she just loved it and loved the fact that we could both put her to bed and read stories.



"There is no way of knowing what the future holds, we don't know when Ollie is going to stop breathing and how long he is going to stop breathing for. He could die tomorrow or he could die in 10 years' time, we have no idea. That is quite difficult to live with and we have to push it to the back of our minds and try and have as much fun as we possibly can.

"At Naomi House we are normal, we aren't different, Ollie isn't different and people don't look at him and ask about him, they don't look or stare. The nurses get it, they see his personality shining through and so many people don't, they pity us, or they talk down to us or to Ollie.

"Ollie is so joyful and he's brought so much to our lives. I remember early in our journey as special needs parents, somebody saying to me that Ollie would teach me more than I could teach him and he would make me a better person. At the time I wanted to stamp my feet and say 'no that's not the way it's supposed to work, and I'm his mum and I want to teach him,' but it's true, he has made me such a better person, and small things that phase most people don't even register in our lives, they're just not important.

"I'm incredibly proud of Ollie, he just lights up a room when he is in it and I know he has brought so much joy to so many people. I really wouldn't change him for the world."

We offer care and support to 423 children and young adults



THINGS I CAN DO



to help Naomi House & Jacksplace

Things I can do...



Hold a Great Big House Party

Take part in their Make Your Will Fortnight Scheme





Sign up for the Clarendon Way Walk or Ultimate Clarendon

Run for Naomi House & Jacksplace



Become a volunteer

Drop off bric-a-brac at the warehouse - now open on Saturdays!

Shopping List...

[] Santa hat [] Collection pot

[] Glow sticks [] Sponsor form

[] Party packs [] Energy bars

[] Hiking boots [] Camera





Visit www.naomihouse.org.uk

Thank 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.

...to everyone who supports our work and enables us to care for the children, young adults and their families across central southern England.

We couldn't do this without you.

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MAKE A DONATION

and help us support families like Ollies now and into the future.

Naomi House & Jacksplace needs to raise £9.2 million a year to continue supporting seriously ill children, young adults and their families. By donating to Naomi House & Jacksplace, you'll not only be helping us achieve this, but you'll also be helping local families who rely on the care we offer.

Discovery Amazing

By donating £10 you could help children and young adults have wonderful sensory experiences with tactile toys helping to develop motor skills and hand-eye coordination.



Fantastic Fun



By donating £20 you could help create magical moments at our hospices. Whether it is water fights in the garden, a leisurely spin on one of our accessible bicycles or experiencing the freedom of our swing seats.

Soothing Water

By donating £50 you could be enabling children and young adults to experience hydrotherapy, allowing complete freedom of movement, alleviating pressure and relieving pain. Families are able to swim together, helping them to make the most precious memories.



Brilliant Care



By donating £250 you could be helping our family of highly skilled nurses care for some of the most medically complex children and young adults in the region. Giggles, cuddles and high quality nursing care are in abundance at Naomi House & Jacksplace.

To donate visit www.naomihouse.org.uk/donate



You can also make a donation by sending a cheque to: Naomi House & Jacksplace, Stockbridge Road, Sutton Scotney, Winchester, SO21 3JE