

# 'I lost my darling daughter but found a new life'

**After the death of her four-year-old, Ellie, Sarah Settelen - runner-up in the YOU/Clarins Most Dynamisante Woman of the Year Award - set up a charity to improve the lives of special-needs children in Russia. And she met another little girl who captured her heart** Report Catherine O'Brien Photograph Teena Taylor

**F**or many of us, displaying photographs is a simple way of telling the shorthand version of our lives. Sarah Settelen's home in suburban West London is adorned with them, but cast your eye over the beaming faces, and quickly you realise hers is a more complex story than most

Among the most prominent images are those of herself and her husband Peter with their adopted daughter Natasha - an enchanting eight-year old with long dark hair and a spirited, gap-toothed smile. Several other frames, however, contain pictures of a more fragile-looking, fair-haired and

blue-eyed toddler. Her name was Ellie. She was born with severe cerebral palsy and died at the age of four. Ellie was the sister that Natasha will never know, and yet their lives are inextricably entwined thanks to the extraordinary journey undertaken by Sarah which culminated this year in her being declared a runner-up in the YOU/Clarins Most Dynamisante Woman of the Year Award.

I have come to see Sarah to talk about Ellie and Natasha and The Promise, a pioneering charity she has established to help orphaned special needs children in Russia. But as we settle on the sofas of her living room, I notice one more photograph - the customary wedding snap. At 45, Sarah is still enviably recognisable as the slender, rather glamorous blond bride she was 16 years ago and yet she says: "When I look at that now I can't identify with the woman I was then at all. I see someone who was doing what she thought she should be doing, but who didn't know who she was."

Sarah's 20-something self was the classic product of what she describes, almost apologetically, as an utterly ordinary upbringing. The

daughter of an engineer father and teacher mother from Birmingham, she read French and business studies at Leeds University and spent several years working as a brand manager. It was the 1980s, and outwardly Sarah looked every inch the thrusting marketing executive - 'But I was just playing the game, I never really fitted in,' she says.

At 27, she met Peter, an actor-turned-communications-consultant who famously voice-coached Princess Diana in the early 1990s. 'He encouraged me to break out - he said I couldn't stay in a job that wasn't feeding my soul. She quit without another job to go. but then secured a position that had my name on it' as corporate fundraiser for Save the Children. She and Peter married in 1991 and the arrival, five years later of Ellie seemed to signal that her life was, at last, on track.

Ellie was six weeks old when Sarah first noticed that her daughter didn't seem to be focusing or making eye contact. 'Everyone told me not to worry, but by three months, it was more obvious that she just wasn't connecting.' Ellie's paediatrician organised eye tests and brain

scans. 'At six months, he said, "I'm very sorry, but I think we are going to have to put a label on this.'" The label was cerebral palsy and, says Sarah, the bottom just disappeared from my world.'

Cerebral palsy is a general term for mobility disorders caused by brain damage. It is a condition with a huge spectrum, but it soon became clear that Ellie's difficulties were among the most profound. She couldn't walk or talk, and doctors told the Settelens it was highly likely that she would never see.

Sarah's role with Save the Children had raised her awareness of myriad childhood afflictions, 'but it had always been "out there",' she explains. 'I had never actually known anyone who was disabled. We didn't know the rules, the language, who we should speak to.'

She battled with the guilt - 'Did I do something during pregnancy that caused this?' - and battled relentlessly with social services and medical professionals to get the care that Ellie needed. By two-and-a-half, Ellie had a place at a fantastic nursery (the same one that cares for David Cameron's disabled son) and Sarah was able to catch up on her emotional backlog. 'I remember being out one day, seeing a boy of Ellie's age running around, and for the first time not yearning for what might have been. Ellie had opened my heart to unconditional love at the deepest level.'

Ellie's death was as sudden as it was unexpected. 'In her final months, she had become more alert and things were looking up for her,' says Sarah. But in January 2000, she was rushed to hospital purple lipped. A flu virus had led to pneumonia. She died five hours later. Sarah recalls watching Peter tenderly scooping her up as nurses unplugged breathing tubes, 'and I wanted to hold her, too, but I couldn't do it straight away because holding her body meant accepting her death and I wasn't ready.'

In the aftermath, the simplest things were among the most painful. 'Walking out of the front door on my own, going out for a meal, watching TV, having a bath knowing that no one was going to need me. For four years I had done none of these things because Ellie had needed care 24/7. She didn't leave a gap in my life, she had been my life.'

As Sarah grappled with this, she did two things that were to change the >>

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Sarah with her daughter Ellie, who inspired her to set up The Promise

<< course of her life. First, she trained as a portage worker. Portage is a widely acclaimed precision teaching system designed to help special-needs children and their parents. It works by breaking down developmental milestones into small steps. For example, the process of putting a toy into a container and taking it out again is something that most children do automatically. The portage worker will break down the process for less able children so that they might learn to pick up the toy first, and then - perhaps with gentle stroking of the hand to encourage them - drop it, before picking it up again. Ellie had been assigned a portage worker, Diane. 'Actually, Ellie was so extremely disabled that she gained less from portage than most children,' Sarah explains. 'But Diane gave me the confidence, through portage, to understand Ellie better. It was only after working with Diane I began to realise that when Ellie was listening to me, she would turn her head and *widen her eyes*. Portage opened a whole new world, and I wanted to learn how to do that for others.'

Sarah's second life-changing decision was to travel to Russia to work as a volunteer in a children's home. 'When Ellie was alive, I had read an article about a little girl just like her who lived in a Russian orphanage. She was disabled, emaciated, and no one ever picked her up out of her cot. The story lodged in my psyche. Ellie's life may have been absolute hell at times, but at least she knew what it was like to be held and to be loved.'

Sarah didn't know what she might achieve in Russia. 'I just had this growing awareness that I had to go there.' In May 2002 she went with a friend to Ryazan, a town 100 miles from Moscow, to work in a baby home housing 150 children under the age of four. One third of them are disabled. 'In Russia,' Sarah explains, 'it's rare to see anyone with Down's syndrome, cerebral palsy or any other disability taking part in normal family life.' Disability carries a



Above: Sarah at a Russian baby home.  
Below: a portage worker at Ryazan



social stigma. Such children are often rejected by their parents and face a lifetime in institutions.

Sarah will never forget taking her first steps into the Ryazan Baby Home. The stench of curdled milk and stale urine hit me, and we saw women in white carrying tiny bundles - children who were no longer loved.'

Later that day, she sat in the playground watching the children play. 'In one corner there was a girl kneeling on the floor, playing with a stick. I went over, picked her up, and realised why she was kneeling. Her legs stayed bent - she couldn't walk. I carried her over to where I was sitting, placed her on my lap and, as I did so, she cupped my face in her hands turned my eyes towards hers, and gave me a huge smile.'

The girl was Natasha. She was three and a half, had cerebral palsy and had been in the home all her life. 'Every time after that when I went into the playground, I sought her out. There was something about her energy - it was as if I already knew her,' Sarah recalls. Sarah continued to work with all the children 'but Natasha I fell in love with.'

In a head spinning telephone conversation, she told Peter what she was going through. 'And he said: 'You have to bring her home.'

In July 2002, Sarah returned to the UK 'knowing I had to give birth to two babies.' Her first mission was to set in motion the adoption process

for Natasha; her second was to create a charity to help the other children that she couldn't possibly make her own. 'I knew absolutely how I could help them,' she says. The one thing that would give them the love and attention, the touch and the cuddles and laughter that they needed was portage.'

She contacted Mollie White, the UK's leading expert on portage, and then spent 18 months raising the £40,000 necessary to establish a portage training programme in Ryazan. In 2005, The Promise recruited and trained its first six portage workers - all local Russian women. A six-month pilot study produced dramatic results. Thanks to half-an-hour's concentrated attention daily, children who could barely crawl began walking, those who were permanently agitated became calmer, more expressive and able to enjoy play. The director of the children's home, who was initially sceptical about the benefits of portage, is now a total convert, and there are now ten portage workers at Ryazan Baby Home.

The Promise has also developed a community portage Service in the town, working with parents of disabled children at home. And the programme has been extended to provide three portage workers in an orphanage at Yelatma, which cares for children aged four to 18. That number will rise to ten workers, reaching a total of 40 children, thanks to another Clarins initiative in November when a limited edition bottle of Eau Dynamisante fragrance goes on sale. A £1 donation from every bottle sold will go to The Promise, which should raise

£10,000 for the charity.

Yelatma is where Natasha would be now, had she not been adopted by Peter and Sarah. When they brought her home in May 2003, she was still unable to walk, hold a pencil or speak anything but the most basic Russian. She was very scared, there were huge adjustments

for her to make,' Sarah recalls. 'It took months for her to understand that this was her home and that these were her toys. In Ryazan, everything was shared - she had never owned anything.'

Natasha today is a bright, effusive girl who attends mainstream school, talks nonstop (English is now her first language), reads fluently, walks with the help of sticks, horse-rides, swims and even water-skis. 'It has been like watching someone come out of a black hole,' Sarah says. There are times when she sometimes gets upset by her disability, but fundamentally she knows that she's utterly lovable. For us, that has always been far more important than whether she can walk ten paces unaided to the front door.'

Natasha was five when she first pointed to photographs of Ellie and asked, 'Who's that?' Sarah explained that before she arrived Mummy and Daddy had had another little girl. There was this awful shock on her face. For a while, she would become very upset that she had never met Ellie. She would have loved to have a sister.

Today, however, Ellie is a comfortable presence in all their lives. Sarah keeps a candle burning on the fireplace in her memory, Natasha cuddles Ellie's teddies, and they dance to the Abba songs that Sarah played to make Ellie happy. 'She was a little girl who couldn't walk, talk or see, and yet she was absolutely life-changing for all of us,' says Sarah. 'I like to think of her as the greatest healer I ever had.'

If you would like to make a donation to support the work of The Promise, visit [thepromise.org.uk](http://thepromise.org.uk) or send a cheque, made payable to The Promise, to 181 Jersey Road, Isleworth, Middlesex TW7 4JQ

£1 from the sale of every limited-edition bottle of Clarins Eau Dynamisante will go to

The Promise

