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Older children in the orphanage

A promise worth keeping
 Sarah Settelen keeps her promises. Perhaps some are more important than others. But none has had a more profound effect than the one she made to her disabled daughter shortly after four-year-old Ellie had died.

Sarah promised that Ellie's death would not be in vain; that she would do whatever she could to help improve the lives of disabled children. It was a solemn promise from a grieving mother made in memory of her beloved daughter.

Eight years on, Sarah Settelen is sitting in her West London home discussing ThePromise, a charity she founded that offers support to disabled children in Russia. It is ThePromise's fifth anniversary.

Did she ever imagine that she would be doing something like this?

"Absolutely not. Absolutely not," says Sarah emphatically. "I would never have thought that I had the skills or the ability to set up something like this."

"But it is a testimony to the strength that we all have inside."

Best Laid Plans

Sarah had always wanted to make a difference. In her early-30s she ditched her marketing career to become a corporate fundraiser for Save The Children. But what she really wanted to be doing was rolling up her sleeves and 'getting out into the field, into Africa... An awful lot of people in corporate fundraising are frustrated aid workers,' she says.

Any serious thoughts of doing aid work in Africa were dashed in 1996 when Ellie was six months old and it became apparent that she was very seriously disabled.

"She became my life because she was so disabled and required 24 hour care," says Sarah. "I had to coordinate her care and make sure that I got all the help we needed. It was a full-time job apart from all the emotional stuff."



Sarah with her daughter Ellie

Fighting for Ellie

Sarah and her husband Peter would fight a draining and long-running battle to get the support they needed.

"We would be tossed around like a hot potato from one agency to the other: Health, Education and Social Services. And at the centre of it all was a little girl who had huge needs. It was a battle and we had to really grit our teeth and be pretty determined."

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"We fought and we fought because we were middle class," says Sarah.

"We fought and we fought because we were middle class"

Sarah Settelen

In the midst of their struggle for assistance, Sarah happened to read a magazine article about a disabled girl in a Russian orphanage, who had no one to care for her and was left abandoned in a cot.

"Yes, we were engaged in this ridiculous and awful battle for Ellie but at least she knows that she is loved and is the centre of our universe. This little child in Russia had been totally ignored by everybody."

The contrast left a lasting impression.

Epiphany

One day, Ellie caught the flu, which rapidly developed into pneumonia. She died aged just four years old.

Nine months after her death, Sarah felt an overwhelming and inexplicable desire to visit an orphanage in Russia. She didn't know where she was going, what she was doing or how she was going to help.

"I felt as though I couldn't have got on with the rest of my life until I had done it. It was like an itch, and I had to scratch it by going there."

And sure enough, soon after her arrival, Sarah would find the answer that would provide the basis for ThePromise and which would allow her to keep her word to Ellie.

"It just came to me. I remember it very, very clearly. It was an epiphany moment and it came to me in a complete package. It almost made me weep with the beauty of it."



Sarah with children at the orphanage

Providing Portage workers in the orphanages could be the silver bullet.

Portage

Portage is a specially-structured educational service and tool for children with disabilities or learning difficulties. It breaks down the child's development needs and then devises games and activities which, through repetition and practice, enables them to make progress.

Sarah had already become a trained Portage worker because of her experience with Ellie, and she knew the difference it could make. In the UK, and in most Western countries, it is a commonly-available home visiting service.

In Russian orphanages, thought Sarah, Portage could be a massive force for good. Not just in helping the children with their development needs, but also, due to the one-to-one nature of the service, offering each individual child precious emotional support as well.

Promise Fulfilled

It took only two months of the six month trial to convince the orphanage director in Ryazan, Western Russia, of the astonishing difference that Portage could make. Children who had previously barely been able to stand up were now walking.

To date, ThePromise has trained up 30 portage workers in Ryazan. Ten work in the baby home where Sarah first volunteered and where the pilot programme was launched. Ten work in the community offering a

home visiting service. And ten are based in the older orphanage for children with more profound disabilities and are effectively bed bound.

As well as the Portage, ThePromise is also a gentle campaigner for the rights of disabled children in the local Duma. The group has struck up such a trust with the local orphanages that it also provides physiotherapy, nutritional advice and, wonderfully yet incongruously, also helps to make cheap furniture.



Nastya with her walking frame

Although Sarah doesn't wish to see ThePromise becoming a huge organisation, she does see it as a model of good practice that can be used in other regions of Russia. Its budget for the current financial year is £150,000: "Not huge but the effectiveness of it and the lives we are changing is incredibly large," says Sarah.

The strength within

Having fought the authorities at home, having endured the heartbreaking loss of a daughter and after overcoming the scepticism of Russian care workers, Sarah Settelen may well wonder how she has found the strength to see ThePromise through its first five years.



Sarah at her home, August 2008

She no longer needs to travel to Russia or devote every waking hour to ThePromise, allowing her to spend more time with Natasha, a little girl she fell in love with at the orphanage and whom she has since adopted.

"For me, the circumstances just came together in a moment that allowed me to express everything that I had experienced: All the positive things and the negative things; the hard times and the good times; the grief, and also to express a huge amount of love."

It shows what good things can come from keeping one's promises.

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