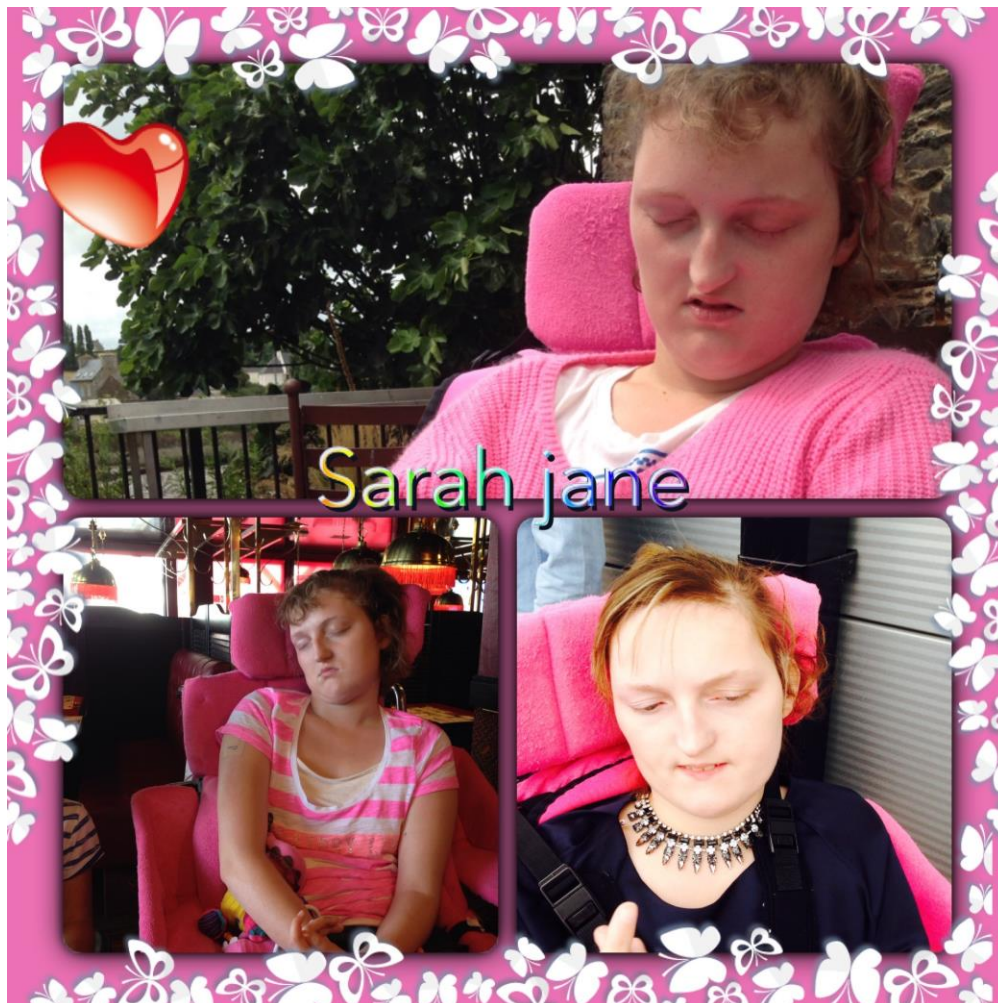


2016 winners

Sarah Jane Price's team:

Louise, Brad, Kelly, Hana and Jared Ellis (her foster family); Dr Emma Husbands (Consultant Palliative Medicine); Dr Rob Estelrich (General Practitioner); Agnes Lawler and the District Nurse Team; Sue Higgins (Epilepsy Nurse Specialist)

Sarah Jane Price's team was nominated by her foster mother, Louise Ellis. Sarah Jane died in 2015 at the age of 21. She was fondly known as 'Princess' due to her love of pink and designer clothes. She had, her foster mother says, "a wicked sense of humour". She loved music, a range of films, chocolate, pretty men, holidays, adventures and the theatre to watch musicals, especially if she was in the royal box. She had a full and active life, despite her disabilities.



Sarah Jane had profound physical and learning disabilities. She had severe cerebral palsy, microcephaly and epilepsy. Her early home life was difficult and events that led her into the care system were heart breaking. But this somehow, when she began to recover from some of

her trauma, made her joy of life greater. She lived with her foster family, the Ellis family, from the age of eight.

In 2014, when her health had started to fail, her foster family never considered not going on this journey with her. Her birth family, advocate and professionals ensured SJ's voice was heard, and all were committed to caring for her at home.

The palliative care team at Gloucester Royal Hospital entered her life. There was no palliative pathway in place for people with additional needs, so this was an opportunity to work together and put one in place. They used generic services and adapted them as required.

Here are just some of the comments from SJ's foster mother, Louise, highlighting what was so brilliant about Sarah Jane's care.

“Emma Husbands, the hospital palliative consultant, was always available (well it seemed that way). If we were worried or concerned she would always come out for a home visit. Her consistency and support was invaluable.

We had a nominated GP, Rob Estelrich. A backup nominated GP was put in place towards the end. This ensured that Sarah Jane got a quick consistent service even when Dr Estelrich was not available. Dr Estelrich was more than a GP for Sarah Jane. He saw us all as his patients and understood that keeping us all well would ensure that we would be able to provide SJ with the care she needed.

Her epilepsy nurse specialist, Sue Higgins, saved the day on many occasions with quick guidance to help manage her epilepsy as it spiralled out of control.

There was excellent advance care planning. The care plan in her home would often change on an hourly basis and the ability to change and adapt and not to procrastinate was the key.”

The judges felt that the following description was just one of the many examples of the excellence of the available support and team working:

“There was a group email system set up which included all professionals and significant care staff where any issues were raised and everyone could see the same information and respond. As an example, if there was an issue with Sarah Jane’s epilepsy such as having significant seizures overnight. The epilepsy nurse may respond with some advice to increase Clobazam, the palliative care consultant could add something such as if this is not working could the nurses come and administer Midazolam via driver, the physio team would look at ways to ensure Sarah Jane was safe during therapy, the GP may add that there would be a prescription electronically at pharmacy, district nurses would add Sarah Jane to their round. This type of immediate responses from a huge group of professionals was invaluable and was an important factor as to why we were able to keep Sarah Jane well and reduced any chance of hospital admissions. It came affectionately known in our house as *Sarah Jane’s medical blog.*”



Sarah Jane and her foster family

Sarah Jane's foster sister Kelly said:

“Emma Husband (the palliative care consultant) was indescribable in the level of support and care she gave Sarah Jane, my sister and myself during the last week of Sarah Jane's life. She rang us every day in order to get an update on Sarah Jane from our perspective and how we were feeling in regards to supporting Sarah Jane. These phone calls were made out of normal office hours and it felt like Sarah Jane and us were really important and that we were not alone in this situation. Emma was able to answer questions, relieve our anxiety and spent as much time talking to us as we needed. Despite us looking after Sarah Jane in her last few days at home I never felt alone or distanced from services. They were a matter of a call or drive away and that knowledge meant I felt, although very sad, I could continue to give Sarah the care she deserved at the end of her life at home where I know she would have wanted to be.”



Sarah Jane towards the end of her life

Even towards the final weeks of life, Sarah Jane continued to enjoy the things she loved, such as going to college. Her foster family were invited to come to college and spend time with her there. At home, Sarah Jane's bedroom became a sensory overload but she loved it, candles were burnt, music was played, her favourite bells still hung above her bed even though she was now too weak to play them. Pink was everywhere.

Most importantly, she was home in the place she loved, with the people she loved and who loved her back. During her final week, she was never left alone. Sarah Jane died with her family huddled in her room all day, telling stories, watching her favourite film, and holding hands as she took her last breath.

It was clear to the judges that Sarah Jane's care during her final months had been outstanding. This clearly depended on having a wonderful and loving family, but this alone is never enough. It also depends on that family receiving a huge amount of support and reassurance; on skillful management of physical, emotional, spiritual and social problems; and on planning ahead. The professionals involved in Sarah Jane's care learned from her situation. They developed new ways of working, which will benefit people with learning disabilities in the future. We are delighted, therefore, to be able to highlight Sarah Jane's care as an example of best practice.