

NEWS

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■ Mark and Ruth Higginson, with children Josie, Amelia, Phoebe and Jamie at their home in St Ives.
Picture: HELEN DRAKE

Two young carers play vital role in helping family cope

When triplets, Amelia, Phoebe and Jamie were born, Ruth and Mark Higginson, were filled with joy. But within six months, an exhausted Ruth had suffered a breakdown. Two of the babies cried constantly and were failing to thrive. Ruth talks to **DEBBIE DAVIES** about the medical diagnosis that changed all their lives. And how two of their children are helping the family cope in roles as young carers

For the first few weeks of their triplet's lives in September 2007, Ruth and Mark Higginson, of Dart Close in St Ives, coped well.

They also had a one-year-old daughter, Josie, so daily life was an endless cycle of feeding and changing nappies. They were exhausted, but contented themselves with making plans for the future – looking forward to the day when the triplets would take their first steps, imagining them walking to school in matching outfits and all four of their children playing together.

But gradually Ruth became concerned about Amelia and Phoebe who were failing to keep up with Jamie.

The girls were losing weight, had severe nappy rash that wouldn't heal and it was impossible to settle them. When they were six months old, Amelia and Phoebe were admitted to hospital for tests.

"It was extremely difficult to watch Jamie thriving but the girls not keeping up," said Ruth.

The tests were not conclusive but it became clear that both girls were severely disabled and would need 24-hour care for the rest of their lives.

"At that point I just couldn't stop

crying and I had a breakdown – I was in complete shock and it felt like I had been hit by a truck," said Ruth.

"It was similar to a grieving process. I felt like I had lost my girls. Lost all those hopes and dreams for the future and all that potential of what they could have become."

A few months ago, Amelia and Phoebe were diagnosed with a rare genetic mutation called Grin2b which is a severe neurological development disorder.

They are thought to be the only children in the UK, possibly the only twins in the world, to have the condition.

Now aged eight, they are unable to communicate, need wheelchairs to move around and their food and drink has to be administered via a tube into their stomachs.

They do not have a regular sleep pattern, are doubly incontinent and have scoliosis (curvature of the spine).

"Sometimes life is crazy, we can't do things on the spur of the moment and just leaving the house is a mammoth task," explained Ruth.

Jamie and Josie, aged 9, are devoted to their siblings and without the practical help and support they offer Ruth and

Mark, the couple would find it almost impossible to manage.

Ruth says Jamie and Josie, who attend Wheatfields Primary School in St Ives, started helping to care for Amelia and Phoebe when they were four or five years old.

"Amelia and Phoebe go to a foster carer midweek, but spend the rest of the time at home where Jamie and Josie help by using a syringe to give their sisters water via their tube, which needs to be done eight times a day each, as well as operating their feed pumps. They operate a lift on their minibus when they go out, ensuring their wheelchairs are securely clamped."

Ruth, and Mark, who is a postman, get very little sleep at weekends, on average only four hours, but Ruth is determined the family will enjoy activities at the weekend just like any other family.

"Josie and Jamie will help by pushing a wheelchair, and it can take up to an hour if Amelia and Phoebe need to be changed, which Josie helps with.

"Josie and Jamie do have extra responsibilities which other children their age don't have, but it's teaching them to be responsible. We want them to enjoy as normal a childhood as possible.

"This is our normal family life and Jamie and Josie have a great input into providing care for their sisters Amelia and Phoebe who we all love very much, and wouldn't want any other way Jamie is a natural at it, I don't know if it is because of his bond with the triplets, all being together in the womb. I am very proud of them."

Recognising the caring efforts of an army of young people