

# Parents are the unsung heroes

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It's a parents worst nightmare, a newborn baby going under the knife to repair a heart defect. If the baby survives, that's when the real work begins for parents. University of Alberta nursing professor Gwen Rempel has seen hundreds of babies on the brink as a former pediatric cardiology nurse; she wanted to find out just what parents go through.

"I'm not 100 per cent convinced that health-care professionals get what these parents are doing," said Rempel. "I think [pediatric cardiology nurses] really pleased to offer what we offer and we're proud of ourselves that these kids are now surviving."

Rempel interviewed parents from across Western Canada, talking to both mothers and fathers about their day-to-day life with a child growing up with a congenital heart defect.

"These parents are extraordinary in what they're doing. Not just what they're doing for their child, but what they're doing to take care of themselves," said Rempel.

In these families, it's all about teamwork. Common public perception is that mothers do most of the work with newborns, but in these families fathers know just as much about their baby. The study found that some of the things both the mothers and the fathers were doing included calculating how much formula the baby needed, feeding the baby and monitoring both the baby's weight and oxygen levels.

"I was very struck by how these couples work together," said Rempel.

"I'm continually struck by that. It's stressful because one parent might be in the hospital all the time, and one's at home trying to keep things spinning," she said. "They really do have to make an effort to keep on the same page."

The study also found that the parents in the study have a great support network. "These parents were never alone and it's family that's with them. It's amazing the amount of time grandparents will spend at hospitals, as well as aunts and uncles."

That's exactly what these parents need, says Rempel. For these kids to survive, the parents need to look after themselves.

"The parents are the ones safeguarding the child's survival. So if the parents are doing okay, there's a better chance the child's going to be okay."

But the parents' ability to succeed starts with asking for help. Rempel says a lot of these parents are just happy their child survived and don't want to ask for anything more. She suggests that health-care professionals need to be stepping up for these families.

"Can we teach them to ask for help? They're already doing what they do really well," she said. "We need to be more pro-active so that they can do even better."

Source: University of Alberta

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