



Anne Harris

Director of Care
Rainbow Trust Children's
Charity
www.rainbowtrust.org.uk

Working with parents with seriously ill children and understanding the impact on their mental health

A new report from Rainbow Trust Children's Charity examining the mental wellbeing of parents caring for a seriously ill baby or child has highlighted that they can often feel traumatised and hopeless.

Parents Matter – The Impact on Parents' Mental Health When a Child has a Life Threatening Illness calls for better access to support for this neglected group of parents, warning that unless it is provided at the right time and in the right way, their feelings of depression, stress and anxiety could escalate into more significant and severe mental health problems.

A survey commissioned by the charity, coinciding with the report, found that 51% of parents believe the greatest impact on their mental health would be their child dying or being diagnosed with a terminal or life-threatening illness.

Families supported by Rainbow Trust, such as Mum Ella-Mae Michalski whose premature twins survived against the odds, tell us that early intervention is crucial in improving their mental wellbeing.

Ella-Mae's is one of many families featuring in *Parents Matter* who are backing the report, keen to raise awareness and eradicate mental health taboos when struggling to cope with caring for a life threatened child.

The report recommends that health and social care commissioners urgently review local respite care funding to include practical and emotional support to families with seriously ill babies and

children. It also seeks to raise awareness of how communities can help and includes a checklist for health and social care professionals to follow when working with parents of a seriously ill child, whether this is in hospital, at home or in the community.

A premature birth or admission to a neonatal unit can have a great impact on a family and it is recognised that parents whose baby is admitted are at increased risk of postnatal depression and post-traumatic stress disorder. This risk can be mitigated if support mechanisms are made available to parents. Many hospitals offer parent support groups that may be facilitated by the unit social worker or psychologist and can offer a safe arena for parents to explore their feelings. However, not all parents will choose to access such a group, with some feeling uncomfortable hearing other parents' stories, which may increase anxiety and stress. Others might not wish to leave their baby's bedside, particularly if they live a distance from the hospital and are visiting for short periods.

Rainbow Trust provides practical and emotional support to families caring for a seriously ill child in certain areas across England. This can include transport to and from hospital, enabling parents to visit without the additional pressures of negotiating traffic and parking. The journey to and from hospital can also provide an opportunity for a parent to sit quietly and have a break or chat to the family support worker. Support can be offered in the hospital and at home following discharge, offering a bridge between the neonatal unit and home. Should a baby die, then the dedicated family support worker can offer ongoing bereavement support for as long as the family needs it.

Rainbow Trust's family support workers offer non-judgemental support to help a parent to manage their feelings more effectively. They can provide rest and respite so that a parent has a chance to do something for themselves, reduce the worry about siblings by giving brothers and sisters quality time with an adult who is there just for them, or reduce practical burdens by helping with transport or helping around the house.

The financial cost of having a seriously ill child in hospital can also be a great strain on parental mental health. Where possible, parents should be given a permit that allows for free or reduced cost

- Do you feel confident that you could spot the signs of a parent or carer struggling with their mental health?
- Do you regularly offer access to psychological support or counselling?
- Is the offer of support repeated at different stages, rather than being a one-off?
- Is support offered in a sensitive and discrete manner, so parents do not feel singled out?
- When parents are interested in accessing psychological support or counselling, do you discuss with them whether there are practical barriers that need to be addressed, such as transport or childcare needs?
- Do you include all relevant professionals in discussions about how families are managing, to ensure that all-round support is provided?
- Have you considered how you can ensure that information is shared effectively between professionals involved with a family?
- Are you able to signpost parents to relevant charities or support groups that offer emotional and practical support?

FIGURE 1 Rainbow Trust's checklist for healthcare professionals working with parents with a seriously ill child.



Bella born at 26 weeks' gestation.

parking when visiting. Parents should be shown options for making drinks and light meals on the unit – most will have a small parents' room that might contain a fridge, microwave and kettle – this should be made explicit to families on admission so they are able to plan accordingly.

Many parents say that they put on a brave face in front of professionals and their children. It may not be obvious how much a parent is struggling. Rainbow Trust recommends that healthcare professionals follow the checklist in **FIGURE 1**.

Case study: A parent's perspective

At her 20-week scan Ella-Mae was told she was 3cm dilated and that she should immediately prepare to lose her twin babies. Following medical intervention and almost seven weeks of bed rest, Ella-Mae and her husband Giovanni's non-identical girls, Bella and Ruby, were born 14 weeks early weighing 910g and 900g respectively.

The twins had chronic lung disease and required oxygen. They were kept in the neonatal intensive care unit from October 2018 until mid-January 2019, during which time they collectively had 10 blood transfusions and experienced several complications. Ella-Mae says: "When I thought the girls may not make it, I felt my world had crashed down around me. I was in a very difficult emotional place. I felt really isolated and alone. It was as if I was fighting a long and lonely battle, despite having people all around me in the hospital. I fell into a really, really deep depression. I can't explain how dark that place was. It was so bad that I could barely get up even to wash. I was never suicidal but I was definitely hopeless."

Ella-Mae and Giovanni had to ring the hospital each day to check if the girls had made it through the night. "There was such a level of fear, a level of depression. It is categorically the worst feeling to be a parent in that situation. My immediate feeling was to run. I tried to detach myself. I didn't want to bond with them, I was so scared they might die and then it wouldn't be so bad."

She began to make excuses for not visiting them, and Giovanni would visit alone. Embarrassed about her poor mental health, Ella-Mae put on a brave face in front of medical staff. The situation worsened when one daughter improved and was moved to a second hospital, so they needed to split their visits between two locations. Ella-Mae would visit to deliver expressed milk for nurses to give to her daughters but one day she didn't feel strong enough to see them at all. A nurse asked her if she was OK and



Ella-Mae at home with Bella and Ruby.

Ella-Mae said no. She was introduced to a psychologist on the ward but did not find it very helpful. Ella-Mae says: "She asked me how the babies were. She didn't see me as a person. They saw me as a mum. They didn't see the fear."

Once the twins left hospital and returned to their home, they still required round the clock care and oxygen for another eight months. At this point the family was referred to Rainbow Trust's Family Support Worker Fiona. "There was no judgment. Fiona would say to me, if you want to cry, cry. If you feel bad, it's OK to feel bad. If you want to swear, go ahead. Saying it's OK to feel bad is so powerful in helping someone."

Fiona helped the couple to adapt to moving the girls back home, taking them to outpatient appointments, assisting the girls with their oxygen and giving Ella-Mae and Giovanni a break. Bella and Ruby are now well, with no long-term health problems.

"I couldn't have done it without my family support worker and Rainbow Trust," Ella-Mae says. "Having her visit for a couple of hours was like coming out of deep water and being able to breathe again. Having someone to talk to and who is good with the girls was amazing."

"Fiona gave us emotional support during the hardest time of our lives. We had no certainty the girls would make it and this support made the world of difference to us. The magnitude of difficulty and the overwhelming rollercoaster that comes with having two sick children is unimaginably hard. We are eternally grateful to Rainbow Trust for helping us get through."

Rainbow Trust's full report and a downloadable checklist for healthcare professionals can be found at: rainbowtrust.org.uk/parentsmatter