

Rainbow Trust neonatal care: caring for families who have a child with a life threatening or terminal illness



Rainbow Trust Children's Charity is an England-wide charity that works with families who have a child with a life threatening or terminal illness. It employs family support workers who work with individual families offering tailor-made emotional and practical support. Families can be referred for support by anyone, provided it is with the knowledge and consent of the family. Director of Care Anne Harris discusses how Rainbow Trust can help families while Joanne Dunkley describes her role as a neonatal support worker.

A bridge between home and hospital

Anne Harris

Rainbow Trust Director of Care
anne.harris@rainbowtrust.org.uk



As a social care provider, Rainbow Trust describes its care as “the essential additional support that families require to cope with their situations.” The charity works alongside healthcare professionals to ensure that families are supported at all stages of their child's illness and, where appropriate, into bereavement support.

Rainbow Trust works with all family members. Crucially it accepts family referrals, *because of a sick child and not for a sick child*. This means that in some circumstances support may purely be for parents, siblings or extended family members. It is there to help with the practical tasks associated with having a seriously ill child such as travelling to repeated hospital appointments or accompanying parents to consultant appointments to listen to new and often bewildering medical information. It can also offer sibling support that enables parents to concentrate on their sick child and allow healthy siblings to continue with life as much as possible.

“It is well documented that admission of the newborn to the neonatal unit has a significant impact on the family with many negative effects.”^{1,2}

Rainbow Trust developed its specialist neonatal family support in 2014 in response to research conducted by the University of Leeds in 2012 that highlighted the number of newborn babies that may require palliative care. Rainbow Trust's neonatal support workers work alongside staff on neonatal intensive care units in London to offer additional support while babies are sick. They are not based on the unit, which means that they remain independent of the unit multidisciplinary team; something that has been

favourably commented on by parents who welcome a slightly more independent source of support.

The neonatal support workers agree with each family the area of support that would be most beneficial on any given day. The flexible nature of the support means that families receive the help they most need at the time it is most required. They can see families on the unit or at home to enable them to come to terms with the additional pressures they are facing (TABLE 1).

Rainbow Trust neonatal support workers can act as a bridge between home and hospital, minimising the sense of separation from the newborn baby. They can be a source of information and support when dealing with medical and nursing staff and can be a constant presence in family life until no longer needed. Their role in supporting brothers and sisters can be invaluable, helping children understand the changes to their family life and offering them time to be children.

Rainbow Trust will continue to support families following discharge from the intensive care unit, allowing them time to adjust to life back at home while still meeting the urgent care needs for their baby.

References

1. Cleveland L.M. Parenting in the neonatal intensive care unit. *J Obstet Gynecol Neonatal Nurs* 2008;37:666-91.
2. Bystrova K. et al. Early contact versus separation: effects on mother-infant interaction one year later. *Birth* 2009;36:97-109.
3. Fowle P.W., McHaffie H. Supporting parents in the neonatal unit. *BMJ* 2004; 329:1336-38.

■ Maternal ill health	■ Complex medical problems to understand
■ Separation from their baby	■ Sudden changes
■ Strange, 'hostile' environment	■ Uncertainty
■ Unfamiliar staff	■ Lack of information
■ Appearance and condition of the baby	■ Physical demand
	■ Financial hardship

TABLE 1 Sources of stress experienced by parents with a baby in the NICU.³

Tailoring support for the whole family

Joanne Dunckley

Neonatal Support Worker

joanne.dunckley@rainbowtrust.org.uk



At Rainbow Trust Children's Charity I am one of two Neonatal support workers in the charity's West London Care Team, and I support many families on neonatal units.

Throughout my career I have always worked with families and children. I started at 16 years of age becoming a nanny and, after having three children of my own, I retrained as a lactation specialist working for the NHS. When this role came to an end I had an interest in working for a charity and, as I had already worked on postnatal, antenatal and neonatal units, the role with Rainbow Trust seemed a good fit.

As a neonatal support worker each week can be different depending on the needs of the families on my caseload. Once I have received a referral from an individual or hospital the first thing I do is meet the family to assess their situation. This can be done at their home or on the neonatal unit. I really enjoy meeting the families for the first time as they are not always aware of how Rainbow Trust can help and they are often amazed with the support we are able to offer.

My initial assessment helps me get to know the family and understand their individual needs. Often families require transport to and from the hospital – I think one of the most challenging parts of my job is battling the London traffic. These journeys can be vital to help reduce the stress for parents getting to hospital and enabling them to open up to me about their fears and concerns of having a seriously ill baby. Sometimes a family already has a good routine and appears to be coping well; the offer of a cup of tea away from their baby's bedside can be just as beneficial and exactly what is needed at that time.

If there are siblings I can go and support a sibling at home or take them on a trip to have some fun out of the hospital while the parents visit their baby. We run sibling arts and craft groups that the children enjoy. Other things I can do are very practical, such as shopping or popping out to get a parent something to eat and drink. In my experience parents can find the days on the

neonatal unit long, tiring and lonely and so they may just want me to sit with them for a while. I can also be there for them during difficult conversations with the hospital medical team and help explain anything they may not understand.

It can be hard for parents to see an end to their time on the unit as their babies can be very premature and fragile and their health can change on a day-to-day basis. I have heard many parents say it is like being on a rollercoaster ride or that it is one step forward and two steps back. I can be there for them as their needs change.

Once families are discharged from hospital some parents no longer require support from Rainbow Trust and others request a transition period at home, which I am very happy to provide. It can be daunting for parents to suddenly be left to care for their baby at home after they have been used to having a team of medical staff around them. After discharge I continue to support the family at home for as long as they need me, if a baby has a diagnosis of a life threatening or terminal illness.

To be a neonatal support worker I would say you need be empathetic, a good listener and have a flexible approach. Sometimes you have to anticipate parents' needs and make new suggestions or tailor the support for the whole family as their needs change. Being a Rainbow Trust neonatal support worker is an amazing job, it is always a privilege to share a family's journey and witness so many parents become capable and confident in caring for their sick or premature babies.



A baby whose family received support from Rainbow Trust.

To find out more about Rainbow Trust Children's Charity visit <https://rainbowtrust.org.uk>

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