



Angie Scales

Lead Nurse: Paediatric and Neonatal Donation and Transplantation, NHS Blood and Transplant

organdonation.nhs.uk

Twitter: @NHSorgandonor

Facebook: OrganDonationUK



Organ donation saves lives – whatever the age of the donor

There has been an increase in organ donation in the overall population in the last 10 years, but this increase has not been realised where donation occurs from paediatric patients and numbers have remained stubbornly static.

Donation from neonatal patients is a very new and evolving area. Prior to 2012 there were only a handful of cases. This has increased to some extent but donation in such an innovative area requires ongoing review. For example in relation to kidney donation studies, looking at the longer term graft function where the donor was less than one month of age led to a review of organ acceptance and the focus is currently on renal transplantation outcomes from infant donors within the one month to two years age group.

There are a variety of challenges faced in donation from small infants and neonates; these range from the specifics required in their end-of-life care, the philosophy of neonatal and family care through to the psychological elements of infant death, impact on professionals and challenges in the donation and transplantation of such small organs.

One thing we do know is that as in paediatric practice, we cannot just apply the same principles

for donation as are applied in adult practice. The National Paediatric and Neonatal Deceased Donation Strategy (**FIGURE 1**)¹ has been developed to specifically address these challenges, predominantly in paediatric intensive care units, but also for the first time including donation from patients within neonatal units.

One recommendation of the strategy is to entirely understand the potential for organ donation from neonatal units and to fully consider the need for these organs given the challenges faced in the transplantation of them. Data are collected by specialist nurses in organ donation (SNODs) on deaths in intensive care units across the UK to determine fully the potential for donation and also to provide information at each stage of the process and the effect on a successful donation, ie identification by the clinical team, referral to the specialist nurse, approaching the family, consent and ultimately whether donation proceeded to successful transplantation.

This data collection is not fully established in neonatal intensive care units (NICUs); in the main this has been due to resources and the availability of SNODs. At present data are collected from approximately 50% of all level 3 NICUs in the UK.



FIGURE 1 National Clinical Lead for Organ Donation Dale Gardiner, Lead Nurse Paediatric and Neonatal Donation and Transplantation Angie Scales and National Paediatric Clinical Lead for Organ Donation Reinout Mildner with the National Paediatric and Neonatal Deceased Donation Strategy¹ at an event for clinicians. The girl on the screen is Anna Hadley, aged 14, who is currently waiting for a heart transplant.

Through the strategy, work has begun to try and establish a robust and sustainable system to accurately collect data while managing the acuteness of SNOD resources. We may assume there is a need for organ donation from neonatal patients, in part due to the urgent need for size-matched organs particularly for hearts where small children face an increased time on the urgent waiting list. However, there is a requirement to fully understand the potential for organ donation from neonatal patients and this has to be balanced with the actual need for organs from infants.

Heart transplantation is clearly not the only possibility and other organs or complex grafts may be more likely to be transplanted from small infants than, for example, kidneys, which are the most likely organ to be transplanted in adults. Understanding of both the potential and need for transplantation of a variety of organs is pivotal to making progress in donation from this cohort of patients.

SNODs will always support families and clinical teams where donation is a possibility and are fully committed to supporting organ donation from whatever age the donor may be and within whichever unit they are cared for. We need to be mindful of the impact of infant death on those professionals facilitating donation who are rarely exposed to child death, as well as clinical teams managing infant death where organ and tissue donation is being facilitated, which can at times impact on their perception of end-of-life care delivery. Support for all professionals involved is a key consideration in developing practice.

It is important to be aware that suitability, offering and allocation may change frequently and therefore the SNOD can provide specific support around suitability and will support families and staff through the whole donation process, from discussions and provision of information to the retrieval operation and post-donation care.

The enthusiasm and willingness of NICU staff to offer organ and tissue donation to families of infants and neonates at the time of their death has been unseen in other areas where donation occurs more routinely, with a focus on something positive coming at a time of such personal grief. Although this comes with the need for adequate management of the expectations of what can be achieved given the challenges we face.

Donation after circulatory death (DCD), where life-sustaining treatment is withdrawn following a decision of futility, has restricted outcomes, none of which are any less significant in the saving and improving of lives of others. However at times this has been seen as a disappointing outcome by some healthcare professionals, for example where the only possibility may be hepatocyte donation and this may disappoint due to lack of knowledge regarding the benefit of this specific transplantation programme.

Donation following the determination of neurological death (DBD) does open the opportunity for donation of a much wider range of organs, many of which are size matched, rare and have children awaiting transplantation (sometimes for extended periods of time). The most likely organ for an adult to donate is a kidney, however in infants we may see cardiothoracic and multi-visceral donation as the only organs where a suitable recipient is identified. Neurological determination of death on neonatal units and for infants less than two months of age has required a change in practice. Guidance on this was published in 2015² and now clinical teams are able to determine death in a way that they previously were not required to consider. This does not come

without challenges, not least in the confidence and competence of consultants and neonatologists in the completion of these rarely seen testing criteria. In determining death by neurological criteria whenever possible, families receive an absolute determination of death. Additionally DBD also opens much greater opportunities for organ donation than if life-sustaining treatment were to be withdrawn.

Cases diagnosed in the antenatal period present a whole host of issues; setting up the donation process to coincide with an elective caesarean section is not without challenges, aside from the other elements previously noted in this article. As with donation in the more conventional process, the specialist nurse can guide healthcare professionals and families through this process and manage the expectations from an early stage. Due to the complexities and recent outcome data from antenatal cases, it is generally only explored when families raise it as an option.

The forthcoming law change in spring 2020 will move organ donation to an 'opt-out' system. This does not cover children under 18 years in England and under 16 years in Scotland, however it is likely to raise the profile of organ donation and families will have a greater awareness of the possibilities around death. This may well lead to more families raising organ and tissue donation as a possibility when their child is nearing the end of their life. There is evidence that families consider the possibility of organ suitability as a measure of the worthiness of their child's life;³ this leads us to the possibility of developing a process that enables families to fully understand if their baby has been considered for organ donation and, if this is not possible, to fully understand the reasons for this.

The strategy seeks to embed organ donation into all end-of-life care discussions at an early enough stage for it to be fully explored. This is concurrently supported by the National Bereavement Care Pathway⁴ and is currently being rolled out across the UK.

Clearly, we all have a role to play in working towards increasing organ and tissue donation from neonates and fully supporting the mechanisms required to do this while balancing the different priorities faced by professionals working in these areas. Working together on the outcomes and recommendations of the strategy will go some way towards addressing these challenges. In the future a more bespoke strategy for further development of organ and tissue donation in neonatal practice may be required, to determine exactly how best practice in this area is defined.

Organ donation saves the lives of others; babies can be a part of this too and giving opportunities for families to have the knowledge that a life has been saved or improved through the death of their baby is a precious gift. Death in infants is relatively rare; we have only one chance for that family to get the process right, so let's continue to work together to do this.

References

1. **NHS Blood and Transplant.** The National Paediatric and Neonatal Deceased Donation Strategy. 2019 online at: www.odt.nhs.uk/odt-structures-and-standards/key-strategies/paediatric-and-neonatal-donation-strategy/
2. **Royal College of Paediatrics and Child Health.** The diagnosis of death by neurological criteria in infants less than two months old. 2015 online at: www.rcpch.ac.uk
3. **Darlington A, Long-Suthehall T, Randall D, et al.** Parents' experiences of requests for organ and tissue donation: the value of asking. *Arch Dis Childhood* 2019;104:837-43.
4. **National Bereavement Care Pathway for Pregnancy and Baby Loss.** Neonatal death bereavement care pathway. 2019 online at: <https://nbcpathway.org.uk/pathways/neonatal-death-bereavement-care-pathway>