

The role of the paediatric cardiac nurse specialist in delivering cardiology services

A paediatric cardiac nursing service was established at Cambridge University Hospitals NHS Foundation Trust (CUHFT) with the aim of providing a contact person for families to identify and link with throughout their cardiac journey. The role ensures support, continuity and coordination of care for neonates and their families across the network. This article discusses the evolving role of the cardiac nurse specialist in a busy level 3 paediatric cardiology service, primarily focusing on the neonatal cardiology services.

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Keywords

cardiac; specialist nursing; neonatal; congenital heart disease services; parental support

Key points

Shelley H., Bradly Russell K., Singh Y., Kelsall W. The role of the paediatric cardiac nurse specialist in delivering cardiology services. *Infant* 2018; 14(5): 188-92.

1. NHS England recommends that local cardiology services (non-specialist cardiac centres; level 3) should have access to cardiac nurse specialist services but most non-surgical centres do not.
2. A paediatric cardiology nurse specialist role was established at CUHFT to ensure high quality clinical care and support for neonates and their families.
3. Regular communication and teamwork with staff, tertiary paediatric cardiology services and parents has been essential for success.

Background

In 2016 NHS England published paediatric standards and service specifications for the provision of congenital heart disease services in England.¹ The importance of level 3 centres (local cardiology services, non-specialist cardiac centres, see **TABLE 1**) was highlighted, emphasising their role in ensuring that children and young people receive as much non-interventional treatment as close to their home as is safe. The implementation of a designated registered children's nurse with a specialist interest in cardiology in each level 3 centre was highlighted as essential to support parents and children.

The role of a clinical cardiac nurse

specialist is well established in level 1 cardiac surgical centres where it is recognised that they play a crucial role in providing family support and high quality clinical care. However, most non-surgical centres have no access to their services and moreover their role in level 3 paediatric cardiology services is not well established.

It is estimated that between five and nine out of every 1,000 babies born in England will suffer from some form of congenital heart disease (CHD).^{2,3} Advances in paediatric cardiology and surgical care have meant that an increasing number of infants with CHD are surviving for longer periods, many into adulthood.^{4,5} This places an increased burden on parents and carers.⁶

Cardiac unit designation	Type of care
Level 1 specialist children's surgical centre (SCSC)	The SCSC must provide appropriately trained and experienced medical and nursing staff sufficient to provide a full 24/7 emergency service, including 24/7 paediatric surgery and interventional cardiology cover. The SCSCs for CUHFT are Great Ormond Street Hospital, the Royal Brompton and the Evelina Children's Hospital, London
Level 2 specialist children's cardiology centre (SCCC)	Congenital heart networks may be supported by one or more SCCC, depending on local need and circumstances. Each SCCC must provide appropriately trained and experienced medical and nursing staff sufficient to provide a full 24/7 emergency service
Level 3 local children's cardiology centre (LCCC)	Congenital heart networks are supported by LCCC, depending on local need and circumstances. The LCCC will have a named consultant paediatrician with expertise in cardiology supported by a registered children's nurse with a specialist interest in children's cardiology, trained and educated in the care of cardiac children and young people

TABLE 1 Fetal, paediatric and adult services work together in congenital heart networks to deliver care through three 'levels' of provider, as described in NHS England's standards of care.¹ Children's level 1 and 2 services work in partnership with level 3 providers to ensure consistent high quality care.

NHS England modelled likely future demand and predicted that the number of operations and procedures in this group is likely to continue to increase at greater than the rate of population growth, putting an additional strain on cardiac centres.⁷

Cambridge University Hospitals paediatric cardiology service

CUHFT paediatric cardiology service is a busy local cardiology/non-specialist cardiac centre dealing with greater than 2,000 patient episodes in the outpatient clinics and providing cardiology support to the neonatal intensive care unit (NICU), paediatric intensive care unit (PICU) and regional oncology services. The demand on the CUHFT paediatric cardiology service is continually increasing. Previous clinical audits and service evaluation projects have demonstrated that the service, working in close collaboration with the Southeast England cardiac network, provides a state-of-the-art high quality service to children with CHD and their families. It has been reported to be working well in providing care for children near to their home and helping to reduce pressure at the level 1 centres.^{8,9} The surgical centre in the network provides a fortnightly specialist outreach service to CUHFT to aid continuity, deliver care closer to the patient's home and provide specialist advice.

A full-time equivalent post for a paediatric cardiology nurse specialist commenced in January 2017 using charity funding from the Addenbrooke's Charitable Trust; the role is job-shared between two part-time nurses. The following sections describe the role of the cardiac nurse specialist under the following six domains:

1. clinical services and patient/family support
2. antenatal diagnosis and perinatal management
3. bereavement support
4. home monitoring services
5. organisation and clinical governance
6. teaching and education.

Clinical services and patient/family support

A major role of the cardiac nurse specialist is to provide support for families and carers, empowering them to participate in decisions regarding their child's care. We aim to do this through open and trans-



Helen Shelley and Katie Bradly Russell with one of their cardiac patients, Josephina, and her mum Emilia.

parent communication throughout their journey, starting from antenatal or post-natal diagnosis. This begins a relationship with the family which will give them a named individual to identify with during any hospital visits, admissions and telephone communications.

One of the first roles was to set up a telephone support line to bridge the gap between hospital and home, provide a point of contact and to establish a crucial rapport with the families.¹⁰ Two days were spent shadowing the cardiac clinical nurse specialist team at a level 1 surgical centre to ensure a consistent service and to build relationships and a sound communication structure across the network. This proved to be an invaluable information-gathering exercise and gave insight into:

- surgical decision-making among cardiologists and surgeons
- understanding organisational processes and communication
- touring the wards and intensive care unit to help prepare families for the types of environments they would face on admission to the specialist centre
- day-to-day issues facing families, eg accommodation and the practicalities of a different hospital setting.

In light of this, support packs were developed to provide families with up-to-date information that has been identified as important to carers.¹¹

The exercise reinforced the importance of robust safety nets for cardiac babies discharged into the community. We work in conjunction with the cardiac centres' home surveillance programme to support families whose babies have a single

ventricle pathology. These babies are particularly vulnerable and support programmes have been found to be beneficial.¹²

To monitor other complex or vulnerable babies we use a framework provided by the cardiac centre; this ensures signs of deterioration are picked up at the earliest opportunity and we liaise with the network when necessary.^{13,14} For out-of-hours emergencies there are clear local pathways and these are displayed as alerts on the hospital computerised patient records. This enables babies to be identified in the emergency department and gains rapid open access to the paediatric wards.

Routine support is provided to address additional needs including developmental needs, lifestyle issues, feeding, medication, information on 'red flags', and signs of possible deterioration or complications.

Communication between healthcare professionals was vital in the setting up of the role; within the trust and among local services. Liaison is maintained with health visitors, community nursing teams, GPs, school nurses, psychologists, dietitians and the local children's hospice. We attend multidisciplinary team (MDT) meetings when necessary.

Throughout their journey, families can experience periods of stress and overwhelming emotions, particularly at the time of diagnosis and when cardiac surgery is required. We are able to directly refer a family for specialist psychological support from paediatric psychologists with experience of looking after families with children with cardiac conditions.¹⁵

At diagnosis we endeavour to be available to offer support and explanation of the child's heart condition. Family and carers will be helped to understand their baby's condition, the possible effects it may have, what signs and symptoms to expect and the treatment that they will receive. Verbal and written information, including diagrams, is given to families and, where appropriate, details of support groups. Where possible we can provide links with other families who have had similar experiences if they feel this would be beneficial.

We are also available at outpatient appointments to provide support and identify the need for further liaison within the hospital and community teams.¹ This may involve links to additional feeding support¹⁶, increased monitoring in the community and liaison with other local

services since there is an increased prevalence of comorbidities in children with cardiac conditions.¹⁷

Over the 12 months since the commencement of the role we have monitored 28 babies a week with an average of 105 home monitoring patient contacts by phone per month.

Antenatal diagnosis of CHD and perinatal management

Approximately 50% of babies born with a CHD are identified before birth but this varies geographically.¹⁸ Mothers whose pregnancies have a high risk of fetal CHD will have been offered appointments in the outreach echocardiology clinic with the tertiary centre paediatric cardiologist. Appointments are in line with the British Congenital Cardiac Association Fetal Cardiology Standards and the NHS Fetal Anomaly Screening Programme.^{19,20}

As the cardiac nurse specialist role evolved it became apparent that support is required during the antenatal diagnosis of a cardiac condition – this is a particularly stressful time for the mother and father and it is important to offer support to help them to understand the diagnosis and the proposed postnatal management plan.²¹ During this time families interact with specialists in fetal medicine and cardiology to learn about treatment options, make informed decisions concerning the management of their baby's care and plan for specific needs after birth. We meet families after the cardiac consultant has explained the diagnosis to give condition-specific information, clarify explanations, answer any further questions, provide psychosocial support and give contact details for relevant support groups.²² Fetal nurses, midwifery councillors and/or NICU councillors are involved where appropriate as parental psychological distress, depression and anxiety are frequent after prenatal diagnosis of CHD and other congenital malformations.^{15, 23} We play a central role in liaising with the councillors and family. Over a nine-month period we have followed 22 babies with complex cardiac problems from the antenatal period to birth, and into the postnatal period.

A monthly update is provided to share information between the neonatal team and the fetal medicine department to improve communication and care consistency by identifying potential high risk births. Parents are offered an



Paediatric cardiology team members Dr Yogen Singh, Helen Shelley, Dr Wilf Kelsall and Katie Bradly Russell.

appointment with the paediatricians with an expertise in cardiology (PEC) to answer questions and develop a clear written perinatal management plan for the baby. This plan is shared with relevant clinicians in CUHFT, the cardiac centre, GP and the parents to help deliver seamless state of the art perinatal management to babies with suspected or confirmed CHDs. Parents are offered a tour of the neonatal unit and also given information about the tertiary surgical centre. Written information about their child's cardiac condition has been shown to be valuable to families.¹⁵ As cardiac nurse specialists, our role is to make sure that all women with a suspected antenatal diagnosis of CHD have a clear perinatal management plan.

We work closely with the fetal cardiac nurse specialists in the surgical centre to share information and to organise tours of the surgical centre for families who feel this might be helpful. Any additional needs of the families can be identified during this time to coordinate care across the network, which is a vital role of the children's cardiac nurse specialist.¹ A care pathway is currently being developed to streamline care and coordination between Cambridge and the surgical cardiology services.

Bereavement support

In a small number of babies the cardiac anomalies are so complex that families may not wish to continue with the pregnancy. Similarly, for some newborn infants continuing treatment may not be appropriate or in the child's best interests and the parents opt for no intervention other than supportive care, for example

newly born infants with complex CHDs, an un-operable condition, underlying genetic conditions associated with very poor outcomes, or those associated with congenital malformations with a very high risk of morbidity and mortality.

Over the last 12 months we have been involved in the care of eight families requiring palliative and bereavement care and support. This has ranged from antenatal diagnosis and termination of pregnancy through to the death of a newborn infant following surgical intervention. We have played a central pivotal role in liaising with other bereavement specialists – including the NICU discharge team, community nursing teams, the local hospice and fetal medicine midwives – to provide holistic end-of-life care in the families' chosen setting.²⁴ We offer a follow-up appointment with our PECs to give families the opportunity to ask questions and have time to reflect on their child's journey. Following the death of a child the parents should be offered the full details of their child's death; this information can be provided at the local or surgical centres depending on the circumstances.

We aim to call families following a bereavement and in addition we send out bereavement cards to offer ongoing emotional support, which has been shown to be valuable to parents following their child's death.²⁵ The details of local support groups and services, for example Petals Charity (<https://petalscharity.org>) and Aching Arms baby loss charity (<http://achingarms.co.uk>), and advice lines are given to families that suffer a neonatal

loss to provide ongoing counselling from a non-NHS organisation.¹

Home monitoring services

For complex cardiac babies in the community, there is weekly communication between neonatal and paediatric community nursing teams visiting the babies and the local and tertiary centre. 'Round robin' emails are sent securely on nhs.net to update the various MDT members. Information is stored on our electronic patient records so that other disciplines caring for the child are able to access the data.

An electronic referral pathway has been developed to ensure that all patients requiring input from the cardiac nurse specialist are identified and offered support and monitoring.

Organisation and clinical governance

Parental support

Service leaflets were developed for families providing the telephone support line number and details on the type of support offered to families. In addition, we have a dedicated cardiac nurse specialist secure nhs.net webmail to communicate with the parents and appropriate professionals. Posters were developed for the ward areas to ensure that the new cardiac nurse specialist role was well advertised among healthcare professionals, in line with recent recommendations.¹ A notice board was created for the NICU to provide families and staff with information on the roles of the paediatric cardiac team and details about the service and cardiac conditions in neonates.

We work closely with the MDT to ensure that families who are finding it difficult to cope are identified and supported by our paediatric psychologists.²⁶⁻²⁹

Digital transfer of echocardiography images

Echocardiography images are sent by the cardiac clinical nurse specialist securely via a picture archiving and communication system to the surgical centres to ensure timely assessment and surgical interventions in accordance with paediatric cardiac standards.¹

Clinical audit and service evaluation

In January 2019, when the service will have been established for two years, we aim to audit it against national standards and use

the results to develop the service and guide performance. We would also like to perform a user satisfaction survey to seek the views of families who have used our service; this has proved useful in adult cardiology nursing services.³⁰

Research

In March 2018 we took on the role of research nurse for the Baby-OSCAR trial that aims to find out whether or not a confirmed large patent ductus arteriosus in very premature babies should be treated with ibuprofen within 72 hours of birth (www.npeu.ox.ac.uk/baby-oscar).

Specialist immunisation

To minimise the risk of missing eligible babies, we initiated the year-round identification of patients who should receive palivizumab respiratory syncytial virus immunisation during the winter period.

Teaching and education

Education is key to empowering families, carers and health professionals to meet each child's needs. It is valuable to promote health and to encourage involvement in planned care. It also serves to communicate the role of the paediatric cardiac nurse across the unit and network.

Parent/carer education

For complex patients where specific care is required, we provide bedside teaching to the nurses and parents; this will also be an area for future development of the service.

We aim to provide parents and carers with information on related issues including lifestyle, nutrition and feeding, medication, cyanosis, increased work of breathing and endocarditis. We have access to a range of written resources to provide support and education for families.

Continued professional development and staff education

It is important that we maintain our own competencies and professional development, building knowledge and skills to enhance care.³¹ We have:

- attended the 15th Introduction to Congenital Heart Disease course in 2017
- shadowed the clinical nurse specialists at the children's surgical centre
- attended train-the-trainer resuscitation training
- completed an immunisation course
- attended the Paediatrician with Expertise in Cardiology Special Interest Group

Paediatric Cardiology Conference

- completed good clinical practice training
- participated in a breaking bad news grief and loss series to help support families pre- and postnatally.

We offer education and support to all professionals, internal and external to CUHFT, and have presented data at the national Neonatal Nurses Association annual meeting and the Eastern Region Paediatric Palliative Care Education Programme.

Conclusions

The introduction of a cardiac nurse specialist to a busy level 3 paediatric cardiology service with an in-house NICU and PICU provides seamless care from fetal medicine through to non-surgical management for infants with CHDs. The cardiac nurse specialist helps to provide state-of-the-art high quality care near to home. This reduces the workload of the consultants, relieves stretched resources and provides a sustainable service for supporting children with CHDs and their families. Regular communication and teamwork with the consultants, staff, parents and tertiary paediatric cardiology services has been essential for success.

Our role as a link professional and point-of-contact in liaising care for patients and supporting families is highly appreciated by patients, their family and other staff members. Given this unique position – a cardiac nurse specialist outside the surgical centres – we intend to review our service regularly and appreciate that the role may further evolve with time. We hope our experiences may offer a leading example to other level 2 and level 3 paediatric cardiology services in the UK.

References

1. **NHS England.** Paediatric standards and service specifications for congenital heart disease services in England. 2016 online at: www.england.nhs.uk/commissioning/spec-services/npc-crg/group-e/e05
2. **British Heart Foundation.** Children and young people statistics, 2013. Online at: www.bhf.org.uk/information-support/publications/statistics/children-and-young-people-statistics-2013.
3. **Public Health England.** National congenital anomaly and rare disease registration service: congenital anomaly statistics, 2015. Online at: www.gov.uk/government/publications/ncards-congenital-anomaly-annual-data
4. **Holst KA, Said SM, Nelson J, et al.** Current interventional and surgical management of congenital heart disease. *Circ Res* 2017;120:1027-44.
5. **Oster ME, Lee KA, Honein MA, et al.** Temporal trends in survival among infants with critical congenital heart defects. *Pediatrics* 2013;131:e1502-08.

6. **Sabzevari S, Nematollahi M, Mirzaei T, et al.** The burden of care: mothers' experiences of children with congenital heart disease. *Int J Community Based Nurs Midwifery* 2016;4:374-85.
7. **NHS England.** New congenital heart disease review: notes from the Clinical Advisory Panel, 4 June 2015. 2017 online at: www.england.nhs.uk/publication/new-congenital-heart-disease-review-notes-from-the-clinical-advisory-panel-cap-4-june-2015/
8. **Chee Y, Kelsall W, Yates R, Singh Y.** Managing neonates with significant congenital heart disease outside specialist cardiac centres: a four-year retrospective study. *Arch Dis Child* 2014;99(Suppl 1): A143.
9. **Anagnostou K, Messenger L, Yates R, Kelsall W.** Outcome of infants with prenatally diagnosed congenital heart disease delivered outside specialist paediatric cardiac centres. *Arch Dis Child Fetal Neonatal Ed* 2013;98:F218-21.
10. **Holmes A.** The role of the cardiac liaison nurse. *Paediatr Nurse* 1996;8:25-27.
11. **Kosta L, Harms L, Franich-Ray C, et al.** Parental experiences of their infant's hospitalization for cardiac surgery. *Child Care Health Dev* 2015; 41:1057-65.
12. **Ghanayem NS, Hoffman GM, Mussatto KA, et al.** Home surveillance program prevents interstage mortality after the Norwood procedure. *J Thorac Cardiovasc Surg* 2003;126:1367-77.
13. **Tregay J, Wray J, Crowe S, et al.** Going home after infant cardiac surgery: a UK qualitative study. *Arch Dis Child* 2016;101:320-25.
14. **Tregay J, Brown KL, Crowe S, et al.** Signs of deterioration in infants discharged home following congenital heart surgery in the first year of life: a qualitative study. *Arch Dis Child* 2016;101:902-08.
15. **Bratt E-L, Järholm S, Ekman-Joelsson BM, et al.** Parents' experiences of counselling and their need for support following a prenatal diagnosis of congenital heart disease: a qualitative study in a Swedish context. *BMC Pregnancy Childbirth* 2015;15:171.
16. **Kogon BE, Ramaswamy V, Todd K, et al.** Feeding difficulty in newborns following congenital heart surgery. *Congenit Heart Dis* 2007;2:332-37.
17. **Razzaghi H, Oster M, Reefhuis J.** Long term outcomes in children with congenital heart disease: national health interview survey. *J Pediatr* 2015; 166:119-24.
18. **National Institute for Cardiovascular Outcomes Research.** National Congenital Heart Disease Audit Report, 2012-2015. 2016 online at: https://nicor4.nicor.org.uk/CHD/an_paeds.nsf/vwContent/home?Opendocument
19. **British Congenital Cardiac Association.** Fetal Cardiology Standards. BCCA: 2012.
20. **Public Health England.** Fetal anomaly screening: programme overview. 2013 online at: www.gov.uk/guidance/fetal-anomaly-screening-programme-overview.
21. **Rychik J, Donaghue DD, Levy S, et al.** Maternal psychological stress after prenatal diagnosis of congenital heart disease. *J Pediatr* 2013;162:302-07.
22. **Williams IA, Shaw R, Kleinman CS, et al.** Parental understanding of neonatal congenital heart disease. *Pediatr Cardiol* 2008;29:1059-65.
23. **Skari H, Malt UF, Bjornland K et al.** Prenatal diagnosis of congenital malformations and parental psychological distress – a prospective longitudinal cohort study. *Prenat Diagn* 2006;26:1001-09.
24. **NICE.** End of life care for infants, children and young people with life-limiting conditions: planning and management NICE guideline NG61. 2016 online at: www.nice.org.uk/guidance/ng61.
25. **Garstang J, Griffiths F, Sidebotham P.** What do bereaved parents want from professionals after the sudden death of their child: a systematic review of the literature. *BMC Pediatr* 2014;14:269 doi: 10.1186/1471-2431-14-269.
26. **Morelius E, Lundh U, Nelson N.** Parental stress in relation to the severity of congenital heart disease in the offspring. *Pediatr Nurs* 2002;28:28-34.
27. **Tak YR, McCubbin M.** Family stress, perceived social support and coping following the diagnosis of a child's congenital heart disease. *J Adv Nurs* 2002;39:190-98.
28. **Uzark K, Jones K.** Parenting stress and children with heart disease. *J Pediatr Health Care* 2003;17:163-68.
29. **Kolaitis GA, Meentken MG, Utens EMWJ.** Mental health problems in parents of children with congenital heart disease. *Front Pediatr* 2017;5:102 doi: 10.3389/fped.2017.00102.
30. **Hatchett R, McLaren S, Corrigan P, Filer L.** An evaluation of a specialist nursing service for adult patients with congenital heart disease. *Int J Nurs Pract* 2015;21:556-65.
31. **Royal College of Nursing.** Children's and young people's cardiac nursing: RCN guidance on roles, career pathways and competence development. 2012 London: RCN.



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