

Role of the Congenital /Adult Congenital Heart Disease

Link Nurse in Level 3 centre

Definition

Link Nurses are defined as qualified nurses, working in clinical areas within the network who take responsibility for participating in the care of a patient (child or adult) with congenital heart disease. They will develop relationships with staff in the specialist centres, with the aim of improving communication channels with patients and families and facilitating education of other staff within their area of work.

The link nurse's usual place of work may be the outpatient clinic, a hospital ward, neonatal unit, community, or palliative care environment; they will have contact with patients with congenital heart disease and their families.

Clinical

- The Link Nurse will support or participate in the congenital cardiology clinics. (This may be one day a week). They will **not** be expected to undertake the role of a clinical nurse specialist (CNS) but have the role of advice, support, sign-posting and an understanding of the congenital heart disease network
- Be confident in undertaking the assessment of children/adults with congenital heart disease in terms of clinical observations as appropriate - blood pressure, oxygen saturations, height, weight, New York Heart Association (NYHA) classification
- Work alongside the visiting consultant and level 3 cardiologists to provide additional support with regards to onward treatment plan and enable the cardiologist see more patients. This may be on the ward, outpatient clinic or in the community
- Provide high quality information and support to patients with CHD & their families
Ensure patients and families are signposted to and can access up to date relevant information and websites
- Provide information about facilities and resources at the Specialist Surgical Centre relating to cardiac surgery, cardiology interventions, transition and transfer from paediatric to adult services and signpost to support for patients with learning disabilities
- Provide contact details to patients and families for Clinical Nurse Specialist, paediatric or adult teams in the Specialist Cardiology or Surgical Centre who will be able to provide more specific advice and detailed support such as: pre-pregnancy

counselling and contraception for CHD patients, lifestyle advice and support and also support for patients and families with end of life care

- Be able to identify and support the high risk congenital heart disease patients in the network and signpost to appropriate additional support
- Support in-patients at the level 3 centre on the rare occasions there are admissions. A telephone advice line **may** be established for the Link Nurse to deal with families' questions and as a point of referral for specialist advice. This would be to respond to non-urgent queries

Education

- The nurse would develop their knowledge and skills by visiting the Level 1 Centre, CHD outpatient clinics, paediatric or adult congenital joint cardiac case conferences and cardiac wards. This will enable them to have a broad understanding of the patient pathway
- Participate in educational opportunities on the diagnosis and treatment of congenital CHD conditions as offered by the Specialist Surgical Centre, CHD network, national conferences, and stand-alone paediatric and adult congenital study days
- Be able to access the network website (where available) for up to date clinical guidelines and education opportunities www.swswhcd.co.uk

Management

- Participate in service developments in the local congenital heart disease service
- Facilitate local education opportunities for other nurses working in the level 3 centre. Communicate with the Lead Nurse for the Network & the Cardiac CNS who supports the level 3 centres
- Work closely with the local clinical educators to facilitate education of staff
- Develop resources for local staff such as teaching boards, education resources and signposting to relevant web based materials
- Assist in keeping a record of the high risk CHD patients in the level 3 centre
- Support and share practice with other link nurses within the local area through network led activities and events

Professional support

Link Nurses will be offered professional support relating to CHD by the Lead Nurse for the Network, Cardiac CNS' and PEC(s)(Paediatrician with Expertise)/Adult Consultant with an Interest in CHD). This would be offered via:

- Link nurse study days
- Opportunities for shared learning/debrief
- Rotation/shadowing at the Specialist Cardiology/Level 2 and/or Surgical Centre/Level 1
- Learning bursts/short teaching sessions at the Local Cardiology Centres from the CNS/Lead Nurse
- Regular contact with the local PEC or Adult Consultant with an Interest in CHD

Audit

- Collect simple data about the numbers of patients supported and the particular type of support given. This information can be used to contribute to support evaluate workload of the role, and contribute to appraisal and revalidation requirements

Relevant Sections of National CHD Standards 2016

www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2016/03/chd-spec-standards-2016.pdf

A17 (L3)	Each Local Children's Cardiology Centre must have identified registered children's nurses with an interest and training in children's and young people's cardiology	Within 1 year
B2 (L3)	Local Children's Cardiology Centres must have locally designated registered nurse with a specialist interest in paediatric cardiology, trained and educated in the assessment, treatment and care of cardiac children and young people	Within 1 year

B4 (L3)	Each Local Children's Cardiology Centre must have a locally designated 0.25WTE registered children's nurse with a specialist interest to participate in cardiology clinics, provide support to inpatients and deal with requests for telephone advice	Within 1 year
B3 (L3)	Each Local ACHD Centre must have a locally designated 0.25 WTE registered nurse with a specialist interest to participate in ACHD clinics, provide support to inpatients and deal with requests for telephone advice.	Within 1 year

E6 (L3)	Nurses working within Local Cardiology Centres must be offered allocated rotational time working in the Specialists Children's Surgical Centre to enhance development of clinical knowledge and skills enabling professional development and career progression. A formal annual training plan should be in place	Immediate
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Written September 2018

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