

SUB-GROUP REPORT

PAEDIATRIC CARDIAC LIAISON SERVICES

BACKGROUND

Cardiac liaison nurses are an essential resource in supporting the family and the heart child in their relationship with the paediatric cardiac services, in understanding and coping with their (child's) condition and in their journey through the care pathways. The service is highly valued by parents and patients. At every meeting with parents during the review visits to units the service was highly praised. At the CHF Conference held in 2002, there was an absolute consensus from parents about the enormous value of the role and a demand for an expansion in their numbers to enable all families/patients whether being treated at tertiary, secondary or primary levels should have ready access to a cardiac liaison nurse.

This paper seeks to clarify the role and contribution of the Cardiac Liaison Nurse (CLN) working within a multi-professional team (Cardiac Liaison Services) to the care and support of a child and family requiring cardiac care. A Cardiac Liaison Service (CLS) describes a multi-professional team which works across organisational boundaries in primary, secondary and tertiary care settings and provides care and support throughout the patient journey of children/young people undergoing care and treatment for congenital and acquired cardiac conditions and their families. Teams may include a variety of professionals e.g. foetal cardiology nurse, bereavement counsellor, social worker and the CLN.

The care required by all children/young people should take into account both their own needs including any technological dependency and the needs of the family, this includes the case of the child/young person for whom active treatment may have ceased and palliative care is being supported. It is accepted that there is no correlation between the severity of the cardiac abnormality and the anxiety experienced. The care and support children, young people and their families receive should be audited and monitored against national and local standards.

Currently there are 23 CLNs working across the UK, all working in a variety of different ways. CLNs make a considerable contribution to the care of children/young people with cardiac conditions and their families and frequently work in a keyworker role. The keyworker should help to direct the child/young person/family to sources of (age appropriate) information and help. The keyworker should also co-ordinate the provision of services by acting as an enabler and facilitator of communication processes between professionals from tertiary, secondary and primary health care environments and social services, education and voluntary organisations where required aiming for a "seamless service". A diagrammatic representation of the role and relationships of a cardiac liaison nurse is included at Fig.1.

THE ROLE OF THE CARDIAC LIAISON NURSE

- A CLN should be a qualified children's nurse with considerable experience in paediatric cardiac nursing and experience/qualification in community care.
- The CLN will act as a bridge between home, community and hospital cardiac care, ensuring continuity of care and effective communication across all boundaries throughout the child/young person's cardiac care pathway.
- The CLN will, in partnership with children and families assess the holistic needs of children, young people and families in relation to their cardiac condition. The CLN

will then negotiate, implement and evaluate an agreed plan of child and family centred care.

- The CLN will have responsibility for the co-ordination of the overall community cardiac nursing management and support of the child and family and will be a specialist resource for the multi-disciplinary management of the child.
- CLNs will demonstrate the implementation of best practice into their care delivery.
- All CLNs must have the appropriate underpinning theoretical knowledge and all newly appointed CLNs must be supervised by colleagues who have the necessary skills, competence and experience until such time they have acquired the relevant degree of expertise.

NURSING ISSUES

Professional development

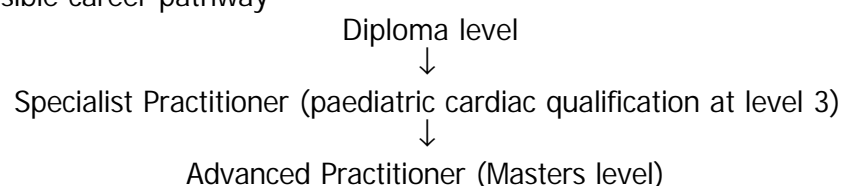
The provision of high quality cardiac liaison care is dependent on the availability of skilled; competent appropriately trained nursing staff. Innovative approaches to provide appropriate educational opportunities should be addressed e.g. distance learning programmes; "cherry picking" modules to make up appropriate graduate and postgraduate learning packages. Education programmes for nurses working within the CLN service will need to develop the competencies required to meet the needs of children/young people and its impact on families. It is recommended that competency based courses are developed which have transferable academic and professional "currency exchange". Transferable educational qualification from one region to another is an imperative. This group recommends that there be agreed course content and standards for all qualifications to assist with this aim and funding of sufficient course places.

All CLNs will successfully complete annual BLS training and updating of clinical skills. All CLNs should be trained in the particular skills necessary to emotionally support parents.

Opportunities for rotation within the clinical network should be managed sensitively and should recognise the professional and personal needs of the individual as well as the organisation. This can provide a wider pool of staff available for recruitment into the service at a later stage. Induction and preceptorship needs should also be considered before and after placements. Within CLN teams the involvement of ward-based and community nursing staff and others e.g. health care assistants or nursery nurses can enhance the team and extends the pool from which recruitment can take place in the future e.g. for parenting support/play service development although time for the necessary support of such staff for training and mentoring will be necessary. Adequate multidisciplinary support should be ensured e.g. administrative, technical and housekeeping staff to the nursing team.

The development of larger teams with skill and grade mix and expanding roles will help to establish a career framework e.g. team leader post, autonomous practitioner, training level posts, advanced practitioners and nurse consultants. To aid recruitment and retention of senior nurses, a career structure must be developed e.g. the framework for higher practice (UKCC).

Example: possible career pathway



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Nurse Consultant

Easily accessible support, mentoring and clinical supervision is essential to the successful development of this high-pressure role

Staffing

The review group recommends that each child/young person with congenital and acquired cardiac conditions and their family should have easy access to a CLN. Currently there is a wide variation between units in how they deliver a cardiac liaison service. This is due to local priorities, limited resources and the varying involvement of other professionals. This makes it difficult at this stage to establish a clear cardiac liaison nurse/patient ratio that would be universally applicable. To overcome this we have established a standard of seven cardiac liaison nurses for a "benchmark unit" *based upon the cardiac liaison nurses undertaking all the tasks in the standards below. It will be for each trust to examine their own service against this benchmark and decide an appropriate establishment relating to its own volumes and staffing configuration.

In practice, nurse staffing establishment should be calculated for each service based upon the number and holistic care needs of children/young people and families aiming to provide continuity of care as well as providing sufficient clinical practice staff to cover annual leave, sickness and study leave. Additional consideration must be given to the geographical location of the caseload. It is therefore likely that services will consist of a minimum of 7 CLNs (based on Benchmark unit). In no case should a unit have less than three cardiac liaison nurses. It is recognised that the service could include the development and deployment of nurses from DGHs to carry out certain parts of the role. The number of children/young people and their families a CLN team is able to care for will depend on the availability of appropriately trained staff and the clinical and support needs of the child/young person and their family and the needs other children and families within the service.

There should be an integrated strategy for retention and recruitment of nursing staff within the cardiac setting across all levels of nursing within the children's cardiac nursing workforce. This may include conjoined recruitment strategies with other units in the clinical network enabling secondment or rotation within the network

Deployment of nursing expertise

As well as looking at the total staffing requirement there is also a need to look at the most effective deployment of resources to meet the new standards.

It has become clear during the course of the Review and from the comments of parents and support groups, that currently services provided in primary and secondary settings are not providing an acceptable level of support to many children and families. Families criticise acute care professionals for their lack of understanding of global family needs but also criticise community professionals for their lack of expertise and knowledge of heart conditions. Links should be made with other providers across the continuum of care to

* Benchmark unit taken as a single site unit with 30 Ward & HDU beds and 10 ICU beds, 2 Paediatric cardiac surgeons and 7 cardiologists undertaking annual activity of 360 surgical procedures (260 open; 100 closed): 460 Medical Procedures (190 Therapeutic catheterisation; 230 Diagnostic catheterisation and 40 Electrophysiology) and offering peripheral clinics at 15 other locations (at PCU 360 clinics per annum with 1400 1st attendances and 4000 subsequent attendances; at other locations 120 clinics per annum with 500 1st attendances and 1900 subsequent attendances)

enhance a seamless service provision and transition between services. Many families regard the support from CLNs as being a key factor in receiving a positive experience. However, most CLNs currently spend a greater proportion of their time within the cardiac unit and the Review Group recommends that this ratio is reversed and increased resources are made available for more effective locally and community based services. In particular to address the child/family's needs at the earliest opportunity, in some cases this will be during antenatal appointments, or within an intensive care environment or within out patients departments or peripheral clinics.

SERVICE STANDARDS

DIAGNOSIS Prenatal

All prospective parents whose baby has been given an antenatal diagnosis of cardiac disease will have access to information, support and counselling from the Cardiac Liaison Services (CLS) at the earliest opportunity. This support should be available between referral and foetal appt and continue between diagnosis and birth. Support should also be available during "immediate surgery". Written information detailing services and support available throughout the patient's journey should be provided to families at this time.

DIAGNOSIS Post natal

CLS/N should liaise with primary care on family situation and be present at out patient/peripheral clinics to explain diagnosis, provide literature, management of condition, act as a call in point if parents are concerned and give the option of receiving copies of the letters sent to GP s.

AWAITING TREATMENT

CLNs will be available to deal with issues raised/advice sought by children/young people and parents in managing condition, care plan, liaison with primary care, etc

TREATMENT: Pre-admission

CLNs or other members of the CLS should be able to see children/young people and parents either at home, in a pre admission clinic or on a planned visit to unit. CLNs will be available to explain treatment, hospital routines, accommodation requirements, family, social and financial issues and to provide child-centred information and preparation for admission when required.

TREATMENT: On admission

CLNs should be available daily on the ward for those children/young people and families who require support.

Consent

CLNs should be available to parents throughout the consent process.

Operation /procedure

CLNs should be available to support the family, if requested.

Post operative

During the postoperative period CLNs should be available to provide support to the family if requested and help prepare the child/young person and their family for discharge.

DISCHARGE

CLNs will work in partnership with ward staff to negotiate and agree a discharge plan and parents should meet with the CLN before discharge and ensure their understanding of community arrangements. Parents should have copy of discharge plan, information about prescribed medication and be aware of how to contact the unit. The CLN should work in partnership with community services and other professionals to ensure that community services and support are mobilised and that secondary and associated conditions are understood by all and care plans developed for these. In complex/palliative care cases the keyworker (who may be the CLN) should initiate a case conference with primary care team and parents and work in partnership to provide care and support.

CONTINUING CARE

The CLN should contact all children/families within one week of discharge from the tertiary centre to evaluate the agreed discharge plan and check that it is meeting the needs of the child and the family. The need for a home visit or further follow up telephone support should be assessed at this time. CLNs should attend out patient and peripheral clinics to provide continuing support and ensure care plans are updated and understood by parents.

The CLN should act as a specialist information resource to other professionals in primary care, secondary care, social services, schools and voluntary services. When required the CLN should have ongoing liaison with these services to support them to meet the needs of the child and family.

Every child/young person/family should have a keyworker, who makes themselves well known to all professionals in the caring and support team. The name and contact details of the current keyworker should be known and readily accessible to the child/young person/family and all professionals.

The CLN may be the most appropriate person to undertake the role of keyworker but the child/young person/family should be able to choose the keyworker from the professionals involved. As the child/young person/family's needs change they should be able to change their keyworker as appropriate.

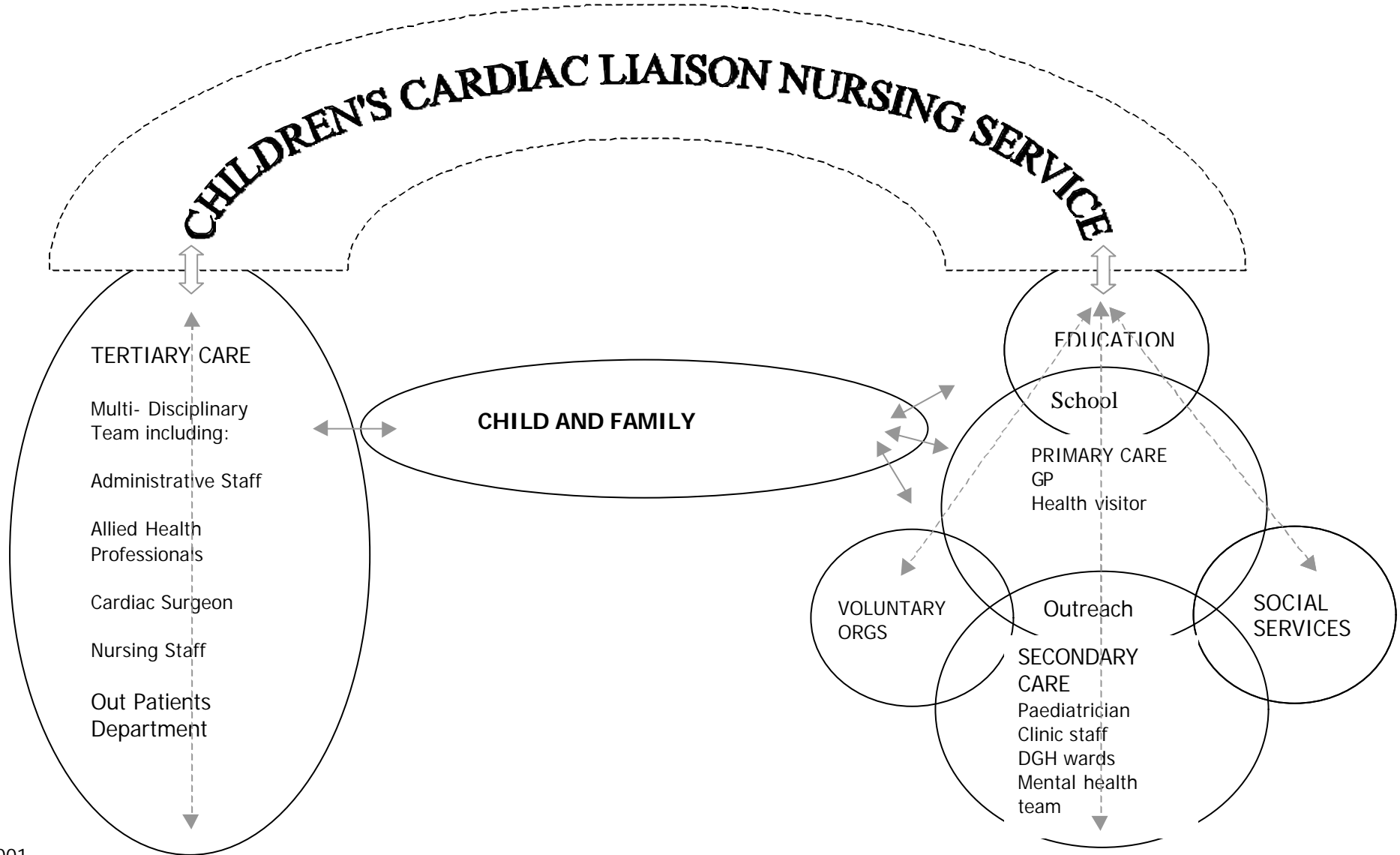
TRANSITION TO ADULT SERVICE

It is recognised that CLNs have an important role to play in transitional care and they should discuss timing/implications of transition with parents and children/young people. Maintaining close links and working in partnership with adult congenital services will facilitate a smooth and "seamless" transfer by appropriate support e.g. accompanied first attendance at adult out patients.

BEREAVEMENT

CLNs should be available to support children, young people, parents, siblings and families through the dying process. When death occurs they can ensure practical/emotional support is available and may assist parents with practicalities/options. CLNs should work in partnership with other bereavement services to ensure the availability of continuing bereavement support.

Fig. 1
 Children's Cardiac Liaison Nursing Service



M Jiggins 2001
 Royal Brompton &
 Harefield NHS Trust