Background

Infants with congenital diaphragmatic hernia (CDH) require intensive treatment after birth, have prolonged hospitalisation and may have associated anomalies and long term problems. Long term issues following discharge from hospital may include respiratory problems [insufficiency doesn't really cover reactive airway problems] pulmonary hypertension, gastro-oesophageal reflux, poor growth, developmental delay, behavioural problems, sensory impairment including hearing loss, hernia recurrence and musculoskeletal abnormalities. Structured follow up of these children facilitates early recognition and treatment of problems and complications and aims to minimise on-going disruption [?stresses] to the child and their family.[1,2]

Follow up recommendations

The Children's Hospital, Boston established the first CDH multidisciplinary clinic in 1990. Publications from this clinic have helped to define the natural history of CDH and provide a model of long term care for these children.[3,4] A CDH clinic was established in the Royal Hospital for Sick Children, Glasgow in 2002. This is now held monthly and routinely involves paediatric surgeons, neonatologists, respiratory paediatricians, developmental therapists and dieticians. Additional support from paediatric cardiology, radiology, audiology and clinical psychology is available as required. The American Academy of Pediatrics published its recommendations for CDH follow up in 2008.[5] Information derived from all of these sources was utilised to produce the recommendations in this document. However, given the geographical challenges of service provision within Scotland, a single model for follow up is unlikely to suit everyone and local modifications will be left to the discretion of individual surgical centres.

Follow up template

In general, children will be seen at 1 month and 3 months after discharge from hospital, then every 3 months until 1 year old, every 6 months until 2 years old and annually thereafter (Table 1). Children who need to be seen more frequently will have Individualised care plans devised.

References

1. Lally and Engle. Postdischarge follow-up of infants with CDH. *Pediatrics*. 2008; 121: 627-632
2. West and Wilson. Follow up of infants with CDH. *Semin Perinatol*. 2005; 29: 129-133
3. Muratore CS, Kharasch V, Lund DP et al. Pulmonary morbidity in 100 survivors of CDH monitored in a MDT clinic. *J Pediatr Surg*. 2001; 36: 133-140
4. Lund DP, Mitchell J, Kharasch V et al. CDH: the hidden morbidity. *J Pediatr Surg*. 1994; 29: 258-264
5. Postdischarge follow up of infants with CDH. *Pediatrics*. 2008; 121: 627-632

Table 1. Recommended schedule of follow up for infants / children with congenital diaphragmatic hernia						
Recommendation	**Timing**					
	Before discharge	**1-3 months**	**4-6 months**	**9-12 months**	**15-18 months**	**Annually thereafter**
General assessment and growth	✓	✓	✓	✓	✓	✓
Chest radiograph	✓	If clinically indicated	If clinically indicated	✓	If clinically indicated	✓
Pulmonary function testing		Infant lung function is not yet routinely available but may be performed in some centres				Consider at ≥ 8 years old
RSV prophylaxis	Consider in the first winter season if less than one year old					
Influenza				Consider if evidence of chronic respiratory insufficiency		
Cardiology review (ECG/echocardiogram)	✓	If existing pulmonary hypertension (PHT) or continuing on therapy (sildenafil) for previous PHT				
Hearing evaluation	✓ Newborn hearing screening	Referral is made at the time of discharge to audiology services to ensure hearing is assessed every 6 months until 3 years old and annually from 3 years to 5 years old				
Developmental screening assessment	✓	✓	✓	✓	✓	✓
Formal neurodevelopmental assessment						Bayley III Screener at 2 years
Upper GI investigations pH study / contrast study / endoscopy	If clinically indicated					
Scoliosis and chest wall deformity screening				✓		✓

Multidisciplinary Long Term Follow-up Guidelines

This guideline is not intended to be construed or to serve as a standard of care. Standards of care are determined on the basis of all clinical data available for an individual case and are subject to change as scientific knowledge and technology advance and patterns of care evolve. Adherence to guideline recommendations will not ensure a successful outcome in every case, nor should they be construed as including all proper methods of care or excluding other acceptable methods of care aimed at the same results. The ultimate judgement must be made by the appropriate healthcare professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan. This judgement should only be arrived at following discussion of the options with the patient, covering the diagnostic and treatment choices available. It is advised, however, that significant departures from the national guideline or any local guidelines derived from it should be fully documented in the patient's case notes at the time the relevant decision is taken.

Proforma for the Cardiological Assessment of Infants with Congenital Diaphragmatic Hernia