



Commentary by the Paediatric Cardiac Society of South Africa (PCSSA) on the European Society of Cardiology Guidelines for the "Management of Grown Up Congenital Heart Disease. The Task Force on the Management of Grown Up Congenital Heart Disease of the European Society of Cardiology."

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- specialized diagnostic imaging of lesions
- arrhythmias and pacemakers
- problems associated with cyanosis and pulmonary vascular disease
- interventional catheterization
- pregnancy and genetic counseling
- comorbidity with coronary artery disease and syndromes
- surgical issues including transplantation
- psychosocial issues and intellectual development
- employment and life insurance

Included in the guidelines is a summary of current management strategies of the commonest lesions seen in grown-ups with congenital heart disease. Many of the recommendations are based on clinical experiences rather than evidence based clinical trials. The lesions covered in this section include atrial septal defects, ventricular septal defects (repaired and un-repaired), atrial septal defects (post-repair), pulmonary stenosis, Tetralogy of Fallot (postoperative), conduits, aortic valve stenosis, sub-aortic stenosis, coarctation of the aorta, patent ductus arteriosus, Ebstein's anomaly, Fontan operations, Marfan's syndrome, postoperative transposition, and congenitally corrected transposition.

Unfortunately there is no explanation regarding the categories of insurance that they refer to.

The following commentary reflects the opinion of the PCSSA.

More and more patients with congenital heart disease are surviving to adulthood and this is largely due to the efforts and successes of paediatric cardiology and surgery over the last four decades. It is a fact, however, that adult cardiologists worldwide are not trained to best manage these patients.

**NEEDS AND REQUIREMENTS**

The task force on the management of GUCH disease of the European Society of Cardiology prepared a document, which details the specific needs and problems of these patients, which include the following:

- the need for transition from paediatric to adult care clinics
- training of practitioners in GUCH

**RECOMMENDATIONS**

The last section of the report deals with specific recommendations, summarized as follows:

1. There should be a transitional service for 12 to 16-year-olds before transfer to adult care.
2. There should be a referral path into a GUCH service.

3. There should be regional specialist GUCH units within adult cardiology programs in multidisciplinary teaching environments. These units should have the resources to investigate and treat patients with complex congenital heart disease.
4. Training programs for specialist staff and cardiologists with "an interest" should be defined and implemented.
5. The provision of health care delivery for GUCH patients and the training should be standardized and coordinated through the ESC.

#### **COMMENT**

1. This guideline is prepared for an entirely different community with physical, financial and human resources massively different from that which we have in South Africa.
2. The public health sector in South Africa has under-resourced tertiary care services with major infrastructural and staff shortages.

Although there is a great need for GUCH services and training, these will have to compete with other greater and more pressing health issues, such as the HIV epidemic that has overwhelmed our existing meagre health structure.

3. There is an urgent need for leadership from government and professional organizations to work towards a coordinated system aimed at optimizing patient care for GUCH.
4. The South African Heart Association (SA Heart), PCSSA and allied professionals bodies ought to develop GUCH services with partnerships between the Paediatric Cardiology and Adult Cardiology fraternity in forming management strategies for this unique and expanding group of patients.
5. It is in the best interests of the patient with GUCH that a cardiologist trained in congenital heart disease supervises their care. This should be incorporated in any guideline on the management of GUCH.