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LETTER TO THE EDITOR

Adult Congenital Heart Disease — Australia and New Zealand: A Call for Optimal Care

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I read with interest, and wholeheartedly support, the Discussion Paper [1] advocating the need for increased resources and improved training for those caring for adults with congenital heart disease (CHD). Gone are the claims that any cardiologist can care for such patients. The need for specialised training has been clearly emphasised by the authors and echoed by others.

In carrying out the survey the authors only reviewed adult congenital heart disease (ACHD) centres across Australia and trumpeted their advantages. They did not take into account the very many patients, currently looked after by cardiologists outside such centres who have gone on to acquire the knowledge and skills to care for such patients. Not only do they include personnel who also work in the ACHD centres but also senior paediatric cardiologists whose patients have opted to stay with them rather than transition to an adult service. The role of such cardiologists within the community is to continue to care for their patients diligently, keeping abreast with current knowledge, recognising problems as they arise, and advocating on their behalf to seek out appropriate interventions when required. The problems that do arise in such patients often tend to be unique. The adult CHD population include many who have had preceding complex problems which may, at times, give rise to specific problems manifesting in adulthood.

An instance comes to mind, while running the Adult CHD Department in Birmingham which services the Midlands of the UK. A 42-year-old woman with cyanotic CHD sought an appointment despite having been told as a teenager that she was inoperable. She had since been seeing a cardiologist who repeatedly bled her. Over recent times she often required admission in a low output state if she drank alcohol. Although blue, her clinical findings suggested that she may have had a protected pulmonary circuit. That was confirmed echocardiographically and by a subsequent catheter. When discussed with the Chief Congenital Heart Surgeon who was also the Director of Cardiac Surgery at the Children's Hospital, he opted, despite his experience, to seek advice from elsewhere as to how best to manage an adult with a univentricular heart and severe pulmonary stenosis. Should she have the pulmonary valve ballooned, proceed to a bidirectional Glenn or have a one stage Fontan circulation completed.

Our Medicare system provides cover for patients seen out of ACHD centres. Many young adults refuse to be financially responsible for their care. If acceptable by the attending cardiologist, such patients may be able to assign their benefits without a co-payment. In addition, working within a community setting allows the cardiologist to choose the best services available across the country for, at times, the very specialised interventions required, rather than being obligated to refer to the staff specialists of the institution he or she may be attached to. A further important benefit is the continuity of care provided by such cardiologists who continue to see their patients over the years. That was evident by our patients having scored the best quality of life of over 4,000 participants from 24 centres over five continents that enrolled in the Assessment of Patterns of Patient-Reported Outcomes in Adults with Congenital Heart Disease—International Study (APPROACH-IS) study [2–4].

An earlier review of women with CHD who successfully completed a pregnancy emphasised the importance both for the cardiologist to be competent in caring for such patients while they were pregnant, and for the attending obstetrician to be conversant with the problems that may arise during the pregnancy from the congenital heart abnormality [5]. Such patients, despite the increased risks that they face, have the

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same motivations to conceive as do their counterparts who do not have a congenital heart abnormality [6]. At the same time, they tended to downplay the seriousness of their cardiac status placing an onerous responsibility on their carers, both the cardiologist and the obstetrician.

There are many advantages associated with centres specialising in ACHD, with the almost daily exchange of ideas and the rubbing of shoulders between the various subspecialists. Yet such centres need to embrace and be inclusive of those that work within the community who strive to provide an optimal service. Benefits may result for all arising from such involvement. The Discussion Paper is timely, emphasising the increasing number of such affected adults with the development of a new subspecialty acquiring knowledge and experience in dealing with the complex problems that may arise [1]. That has only come about following the success story of the management of congenital heart disease through infancy and childhood.

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