

From the Executive Editor

The pursuit of excellence

“Those who attain to any excellence commonly spend life in some single pursuit, for excellence is not often gained upon easier terms.”

– Samuel Johnson (1709–1784)

A FEW YEARS AGO, I SAW IN MY CLINIC A PATIENT who had recently had undergone a Fontan procedure for tricuspid atresia. His mother did all the talking. She was really pleased with the result of the operation. “For the first time he can keep up with me when we go shopping”, she explained. Gratifying, I suppose, but afterwards I had a deep sense of failure about the patient. He was 53-years-old, and his mother was nearly 80. Because he had congenital cardiac disease, the system, including both his mother and me, was still treating him, a mature and intelligent adult, like a child. Whilst he had a very good surgical outcome, I felt we had let him down. The treatment of congenital cardiac disease is built around the needs of young children, and not even older children and young adults, let alone mature adults. In the developed world, services for older patients are generally underdeveloped, or simply do not exist. We could comfort ourselves that we are the victims of our own success. Children with congenital cardiac malformations are now surviving to adulthood in increasing numbers, but in reality we are victims, or rather our patients are victims, of our lack of foresight and vision.

The title of this journal is *Cardiology in the Young*. You may wonder then why we are publishing the 2003 Mannheimer Lecture about the care of adults with congenital heart disease.¹ We, of course, have a long tradition of publication of previous Mannheimer Lectures, and are delighted to be able to continue the trend. On this occasion we make no apologies for looking beyond the age of patient implied in our title, for as Dr Webb makes clear, the care of our patients as they grow into adults should be one of our most pressing concerns. As he spells out, congenital cardiac disease can no longer be viewed as a malady of childhood. The number of adults with congenital cardiac disease now is as great, if not greater, than the number of affected children. The picture he paints of the lack of preparedness for this sea change in prevalence in virtually all developed countries is alarming.

Dr Webb argues for the establishment of centres of excellence for the management of adults with malformations deemed to be at medium and high-risk in linked regional centres providing a limited range of facilities. I have an argument with the concept of “centres” of excellence, which I will come back to, but I have no argument with the ambition of achieving excellence in the care of these patients. As Samuel Johnson wisely indicated, excellence in any field comes only from those who specialise. The need to develop a cadre of well-trained and experienced clinicians expert in the management of adults with congenital heart disease is urgent. These must be doctors that specialise in this field, not those who dabble in it. Paediatric cardiologists, such as myself, have no place seeing 53-year-old patients. Similarly, cardiologists who specialise in acquired coronary arterial disease have no place managing patients with congenital cardiac malformations.

While this vision of what must be achieved is clear, the difficulties of getting there are many, and they will vary in different countries. First, we must recruit and train the specialists, not just medical specialists, but specialists from all clinical professions. This will not be easy if this is not seen as an attractive speciality in which to work. There is already a shortage of paediatric cardiologists in many countries, and adult cardiologists are likely to be attracted to the more lucrative and well established management of acquired cardiac disease. Secondly we must establish an infrastructure of supporting services. It is here I disagree with Dr Webb and his advocacy of “centres” of excellence. We must create *services* of excellence, and services that are built around the needs of our patients, not around the needs of institutions. While some procedures, such as surgery, interventional procedures and invasive electrophysiology, will always need to be centralised, the majority of care needed by the patients require does not. We need to get this balance right. The best way of doing this is by making sure that

patients have a powerful influence over the design of the services. After all, the patients are adults who have lived with their congenital malformations, disease and understand their day-to-day implications much better than even the most experienced doctor.

To be fair to Dr Webb, he makes many of these points. He writes of networking and collaboration between centres. He emphasises the importance of advocacy by specialists, but also by patients themselves. His message is important, and one that should concern everyone who has an interest in congenital cardiac disease. Creating excellent services for adults with congenital cardiac malformations is undoubtedly a major challenge, that will take several years to achieve, but it is one that cannot wait.

The omens, I am afraid, are not good. Previously in this space I have written about the challenges of re-configuring services for children with congenital cardiac disease.² This is a challenge in many countries, but I focussed on the experience here in the United Kingdom. Eighteen months on, what has been achieved? Well, at the time of writing, the answer is very little. The resistance to change is very great, echoing some of the concerns Dr Webb expresses about “lack of vision” in the development of services provided for adults. To paraphrase Dr Johnson, excellence in services for patients with congenital cardiac

disease, be they children or adults, will not be “gained upon easy terms”. The moral imperative I described of ensuring that our services for children with congenital cardiac malformations are capable of providing the best possible outcomes remains. To that, we must add the urgent need to ensure services are created that fulfil the requirements of the growing population of adults with congenital cardiac disease. We must involve patients and families in this work, so that the services provided truly reflect their needs. Pursuit of excellence is a challenge for us all, but for the sake of the children for whom we care, most of who will now live into adult life, it is one to which we must rise.

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References

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2. Baker E. The greatest good to the greatest number. *Cardiol Young* 2002; 12: 209–210.