

# Employment and insurance for young adults with congenital heart disease

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## Abstract

**Objective**—To determine the life and health insurability and employability of young adults with congenital heart disease.

**Design**—Questionnaire study.

**Setting**—Cardiac department of a tertiary referral hospital for children.

**Patients**—Young adults 18-30 years old with a variety of congenital heart defects, both simple and complex, including postoperative patients.

**Main outcome measures**—Availability of insurance at normal or high rates, with or without special conditions or exclusions. Prospects for employment.

**Results**—Questionnaires were sent to eight large life insurance companies, five health insurance companies and, 15 employers, and 26 replies were received (93%). The consensus for life insurability was that young adults with mitral valve prolapse without regurgitation, postoperative ductus arteriosus, and aortic coarctation were insurable at standard rates. Those with any of the other heart defects listed were either insurable at high rates, or in the case of many lesions, not insurable at all. The consensus for health insurance was that insurance was available, but with complete exclusion of benefit for the cardiac disorder. Employment prospects were good for those with simple defects, but poorer for those with complex lesions.

**Conclusions**—Prospects for insurance and employment for young adults with complex congenital heart lesions are poor. Inconsistencies found in insurance and job policies may be due to lack of appropriate guidelines for the outcome of young adults with corrected and uncorrected congenital heart disease.

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about which many patients and their parents have concern, but few data are available. The American Heart Association has published recommendations on life insurance<sup>3</sup> and health insurance,<sup>4</sup> but no such guidelines exist in the United Kingdom. In particular, the extent to which insurance companies agree with American guidelines or with each other for rating young adults with congenital heart disease is not known.

Employability of this population may be based on current cardiovascular state, the likely sickness and absence record, possible premature curtailment of career, and pension planning. No guidelines for employment of these patients are currently available. Some larger employers (for example Royal Mail, British Telecom) have established occupational health services, and may therefore seek employment advice from their occupational physicians for individual applicants. For the vast majority of employers who do not have occupational health advisors, however, the absence of employment guidelines is likely to result in inconsistencies of policy. We therefore undertook this survey to find the employment and insurance prospects for young adults with congenital heart disease in the United Kingdom.

## Methods

### INSURANCE

A questionnaire covering 20 common congenital heart defects before and after operation (see table 1 and appendix) were sent to eight of Britain's largest life insurance companies and to five of Britain's largest health insurance companies. This included simple stratification of lesion severity where appropriate. Companies were asked to assume that in each case the applicant was 18-25 years old and symptom free, and to state whether the subject was insurable at standard rates, high rates, or not at all.

### EMPLOYMENT

Questionnaires were sent to 15 employers. These covered the conditions of repaired septal defects, repaired tetralogy of Fallot, repaired coarctation of the aorta, valve replacement, Fontan procedure, Mustard or Senning repair of transposition of the great arteries, and post operative arrhythmia. A less complex questionnaire was sent to employers because few were thought to have medical consultants on the staff (unlike large insurance companies). Answers were sought from

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Recent advances in medical and surgical treatment of congenital heart disease have led to the survival of increasing numbers of young adults with a range of cardiovascular abnormalities. It is estimated that over 500 000 patients with congenital heart disease have reached adulthood in the last 30 years in the United States alone,<sup>1</sup> and of these about 90% are symptom free and well.<sup>2</sup> Employment prospects and insurability of these young adults are practical aspects of life

## Life insurability of adults with congenital heart disease

Defect	Normal rate	High rates	Decline
AR:			
Mild		*	
Moderate		*	
Severe			*
AS:			
Mild		*	
Moderate			*
Severe			*
MR:			
Mild		*	
Moderate		*	
Severe			*
MS:			
Mild		*	
Moderate		*	
Severe			*
MVP (no regurgitation)	*		
MVR		*(1)	
AVR		*(1)	
Double VR			*(1)
PS:			
Mild		*	
Moderate		*	
Severe			*
Ebstein's:			
Mild			*(3)
Moderate			*
Severe			*
Postop			*(3)
ASD:			
QP/QS < 2		*	
QP/QS ≥ 2		*	
Postop		*(4)	
VSD:			
QP/QS < 2		*	
QP/QS ≥ 2		*	
Postop normal		*(4)	
Postop ↑PVR			*
PDA:			
Preop			*
Postop	*		
CoAo:			
Mild			*(3)
Moderate			*
Severe			*
Postop normal	*		
Postop ↑BP		*	
Tetralogy:			
Preop			*
Postop			*(5)
TGA:			
After Mustard/Senning			*
After arterial switch			*(6)
TAPVR:			
Postop		*	
Truncus:			
Postop			*
Fontan procedure			*
CCHB		*(7)	

AR, aortic regurgitation; AS, aortic stenosis; ASD, atrial septal defect; AVR, aortic valve replacement; BP, blood pressure; CCHB, congenital complete heart block; CoAo, coarctation of aorta; MR, mitral regurgitation; MS, mitral stenosis; MVP, mitral valve prolapse; MVR, mitral valve replacement; PDA, patent ductus arteriosus; Postop, postoperative; PS, pulmonary stenosis; PVR, pulmonary vascular resistance; QP/QS, pulmonary to systemic shunt; TAPVR, total anomalous pulmonary venous return; Tetralogy, tetralogy of Fallot; TGA, transposition of the great arteries; Truncus, truncus arteriosus; VSD, ventricular septal defect; †, raised; 1, policy limited to 25 years after operation by one company; 2, normal rates offered for these conditions by two companies; 3, normal rates offered by one company; 4, reducing to normal rates after one to four years by two companies; 5, high rate policy for short duration available from two companies; 6, high rate policy for limited duration by one company; 7, declined by one company.

a variety of employers: several large government employers—for example, British Rail, Royal Mail, Army; two large supermarket chains, two hospitals, two large private firms (one legal, one banking), and three small businesses (a newsagent, a dry cleaner, and a building contractor). In every case the insurer or employer was asked their policy for an otherwise healthy and adequately qualified applicant of 18–25 years of age. All replies were treated as confidential for the purposes of publication.

### Results

Replies were received from seven of eight life insurance companies (from the chief or

deputy chief underwriter), from all the health insurance companies and from 14 of 15 employers (overall response rate 93%).

### LIFE INSURANCE

Four insurers responded by answering our questionnaire in full. The table gives the consensus of their responses. There was a high degree of agreement between companies for most conditions, but there were some important discrepancies. For example, subjects with mild or post operative Ebstein's anomaly of the tricuspid valve were uninsurable with three of four companies, but insurable at normal rates by the other. Those with congenital complete heart block were insurable at high rates by three of four companies, but were declined insurance by the other. There were also some inconsistencies in policy for post operative patients with tetralogy of Fallot, double valve replacement, or the arterial switch procedure for transposition of the great arteries (table).

Three insurers were only able to respond in general terms. Their policies were similar if a defect was of mild or moderate severity or had been corrected, life insurance was available at normal rates, but was subject to an exclusion for the disclosed condition. If the defect was severe, cover might be rejected completely. A medical report from the patient's physician would be sought before any applicant was rejected.

### HEALTH INSURANCE

No company responded by answering our questionnaire in full. Four companies replied that if a child is a subscriber at the time of discovery of the heart defect, insurance would continue until the age of 18 or 21 years under the family policy. Thereafter a new policy must be issued for the person with the heart defect. Any young adult who declares a congenital heart defect (before or after surgery) would have a policy underwritten to exclude future benefit for medical or surgical treatment for that condition. None of these four insurers would reject health insurance completely for these people, but the heart defect would not be insurable. The other company replied only that all medical underwriting took place on a case by case basis, with reference to the patient's own physician and the company's medical advisor.

### EMPLOYMENT

Replies were received from 14 companies and were written by occupational health physicians (four), company medical advisors (four), or directly by company management (six). In general, large government organisations and public companies had occupational health or physician advisors on the staff, whereas private firms and small businesses had none, and decisions were made directly by the employers. The respondents were optimistic about job prospects for young adults with simple or totally corrected heart defects, but less favourably disposed to those with complex or only partially corrected problems.

**Appendix: Questionnaire sent to insurance companies**

<p>For the following conditions, please indicate whether insurance is</p> <ul style="list-style-type: none"> <li>● Available at normal premiums for age, with or without special conditions</li> <li>● Available at higher premiums</li> <li>● Unavailable</li> </ul> <p>Please assume in each case that the applicant is aged 18–30 years and is asymptomatic.</p>				
	<i>Available at normal rates</i>			
<i>Condition</i>	<i>No conditions</i>	<i>Special conditions</i>	<i>High rates</i>	<i>Not available</i>
<p><b>Aortic regurgitation:</b>                  Mild                  Moderate                  Severe  <b>Aortic stenosis:</b>                  Mild                  Moderate                  Severe  <b>Mitral regurgitation:</b>                  Mild                  Moderate                  Severe  <b>Mitral stenosis:</b>                  Mild                  Moderate                  Severe  <b>Mitral valve prolapse:</b>                  No regurgitation                  Previous mitral valve replacement                  Previous aortic valve replacement                  Previous double valve replacement  <b>Pulmonary stenosis:</b>                  Mild                  Moderate                  Severe  <b>Atrial septal defect:</b>                  Small shunt                  Large shunt                  Postoperative  <b>Ventricular septal defect:</b>                  Small shunt                  Large shunt                  Postoperative, no shunt                  Postoperative, increased pulmonary vascular resistance  <b>Patent ductus arteriosus:</b>                  Preoperative                  Postoperative  <b>Coarctation of aorta:</b>                  Mild                  Moderate                  Severe                  Postop normotensive                  Postop hypertensive  <b>Tetralogy of Fallot:</b>                  Preoperative                  Postoperative  <b>Ebstein's anomaly:</b>                  Mild                  Moderate                  Severe                  Postoperative  <b>Transposition of great arteries:</b>                  Post-atrial baffle                  Post-arterial switch  <b>Total anomalous pulmonary venous return:</b>                  Post-repair  <b>Truncus arteriosus:</b>                  Post-repair                  Post-Fontan procedure                  Congenital complete heart block</p>				

Responses fell into one of four categories:

(a) Employment is based solely on a functional assessment at the time of application. If applicants seemed physically capable of performing the required duties, they would be eligible for employment. This response was received from six employers, two of whom had occupational health advisors.

(b) Employment is based on a functional assessment and a medical opinion from the applicant's own general practitioner or cardiologist, or the company's own medical advisor. This might take into account prospects for future sick leave as well as current ability (from four employers).

(c) Employment is based on current ability to perform the task, future prospects for

absenteeism, pension prospects where entry to a business is linked to entry to a pension fund, and future prospects of premature death or ill health in midlife, resulting in early career curtailment (from two employers). In this case, some young adults with heart disease might be at a disadvantage if they apply for jobs with a long period of apprenticeship or training.

(d) Employment is excluded for candidates with heart disease (from two employers). Other than the armed services, no employer had predetermined standardised policies for persons with a cardiac history. Several commented that the lack of employment guidelines and the ignorance of the long-term prognosis of some conditions may adversely

prejudice the chances of some applicants with heart disease gaining long term employment, particularly for those with complex lesions. Two company medical advisors admitted a lack of knowledge of what some of the listed conditions represented.

### Discussion

Most young adults with simple congenital heart disease can get life insurance (often at high rates), health insurance (with exclusion of their heart defect from the benefits policy), and employment. Most young adults with complex heart lesions cannot get life insurance, health insurance for their heart condition, or a job with long training programmes or linked to a pension fund.

One factor that greatly influences employment and insurance prospects is the severity of the disorder, as indicated by the applicant's physician. For example, a patient with mild aortic stenosis is eligible for life insurance, but one with moderate disease might be declined. Therefore, accurate grading of such lesions is of great importance.

The consensus of British life insurers for rating applicants with congenital heart disease (table) can be compared with a survey of American life insurers prepared by Truesdell *et al.*<sup>5</sup> Results are broadly similar to those in our own survey, although most United States insurers accepted young adults after a Mustard or Senning procedure for transposition of the great arteries, whereas these subjects are declined by United Kingdom companies. Many insurance companies and doctors in Britain refer to data on medical selection of life risks compiled by Brackenridge,<sup>6</sup> who suggests that most subjects with complex congenital heart lesions are uninsurable, and that those with simple lesions be insured only at high rating. These recommendations seem unduly harsh on the basis of more recently available data concerning the natural history; for example, young adults with mild pulmonary stenosis<sup>7</sup> and those who have had successful repair of small atrial<sup>8</sup> or ventricular septal defects<sup>7</sup> have an excellent long-term prognosis. By contrast some other ratings seem generous, such as normal rate insurance for postoperative coarctation of the aorta, given the recognised hazard for early mortality in large series.<sup>9,10</sup> There are some significant inconsistencies in life insurance ratings between companies; therefore young adults declined by one company should "shop around" several others at which they may be insurable, albeit at high rates.

Inability to get health insurance is probably not critical for most young adults in Britain, where their care can currently be undertaken by the NHS. Inability to get life insurance, however, may be a serious disadvantage to a young adult who is married with or without dependent children and is looking for financial security for the future. Furthermore inability to gain life insurance may also make it difficult for many young adults with heart

disease to buy their own home, as mortgage companies often require applicants to hold life insurance as suitable collateral.

There is no consensus among employers concerning prospects of young adults with heart disease. In part this may result from the fact that actuarial survival statistics are not available for most defects after early adult life.<sup>11</sup> Most employers would like to think that new employees, particularly those who require on the job training, will still be healthy when they reach retirement age. Some young adults under our care have found employment difficult to find, even if they are symptom free and have a good prognosis. They claim that some employers are wary of any young person who admits to having had a heart condition, whatever the details. As a result many patients conceal their cardiac history from prospective employers. In the United States, the National Rehabilitation Act of 1973 has improved the employment prospects for any patient with a handicap, as emphasis must now be on the present capacity of a person to perform a given job rather than on projections of future deterioration; no such law exists in Britain. The present capacity for a job relates to physical capability, which is normal in many young adults with congenital heart disease,<sup>12</sup> intellectual capacity, which is also usually normal in these subjects,<sup>13</sup> and the requirement for any special skills, such as driving or flying. In this case safety of work colleagues or members of the public may be endangered if patients at risk of sudden disability or death are employed, and separate recommendations for driving and flying are available for young adults with congenital heart disease.<sup>14,15</sup> Thus most patients with a postoperative congenital cardiac defect should have access to employment. Specialised centres for the care of young adults with congenital heart disease exist in Britain, and have a role in defining functional capacity and long-term survival prospects of this group,<sup>16</sup> and in aiding individual patients in their search for both employment and insurance.<sup>17</sup>

As the paediatric cardiac successes of the modern era reach adulthood they face problems of both a medical and social nature. Although many with simple defects may get insurance and employment, prospects are less bright for those with complex defects or residual postoperative problems. Current practice is not based closely on the available knowledge of natural history of congenital heart disease. As these data on natural and post operative survival become available, guidelines for employers and insurers should be devised. In the absence of such guidelines, some individual companies have set their own policies for young adults with congenital heart disease. Unfortunately many other companies have no policies on this subject, and in these cases it is the patients who are inappropriately disadvantaged.

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