

## **Heart Care Partnership (UK)**

Newsletter - August 2003

The multi-disciplinary team of cardiac rehabilitation and prevention professionals has always held holistic care of the patient in their family at the centre of their concerns. The Fifth Joint Report on Cardiothoracic Services<sup>1</sup> from the Royal College of Physicians and British Cardiac Society and affiliated colleges emphasised the Patient Perspective on services. During the last 18 months the British Cardiac Society has hosted steering group meetings for the new Heart Care Partnership of Cardiac Patient and Carer Associations to eventually become another affiliated group and to truly complete the multi-disciplinary membership of the Society. Preservation and support of individual, and often very focussed groups, lies at the core of this initiative whilst uniting common agenda themes for action. The organisations listed below have participated in initial activities and/or are being invited to join the constituted partnership on the 18 September at Fitzroy Square. I should particularly like to thank the British Heart Foundation, committed to further develop their Heart Support Groups, for the financial support they have so far provided towards educational initiatives on 'Hearty Voices' and information leaflets for the Pulmonary Hypertension Association, Cardiomyopathy Association, Cardiac Risk in the Young and Children's Heart Federation, whose Director, Shirley Law, first drafted a constitution for HCP(UK) along the lines of her Federation. The British Cardiac Patients Association has shouldered much cardiac patient representation work eg the NSF for CHD, through their liaison officer, Eve Knight, but hopefully the load can now be shared and their outgoing Chairman, Douglas Broadbent, has been most supportive of our efforts. Useful liaison towards this goal over the last year had involved other groups, for instance, Stephanie Cruikshank of the Cardiomyopathy Association in NICE consultation for heart failure, BBC broadcasts, the Royal College of Physicians and brought in new emerging groups from PALS, CHD Collaborative, Expert Patients and a new potential patient expert group from British Cardiac Society Members' proposals. Regionalisation of Heart Care Partnership (UK) though the developing cardiac networks may be an obvious idea to link the new with more established patient groups. I attended, on behalf of the British Cardiac Society, a volunteer's summit at Westminster in March. The potential value of the voluntary sector is certainly appreciated and, therefore, how much more might be achieved by reducing barriers to volunteering and championing its importance and ways it can share resources and spread good practice, our initiative exemplifying progress.

### Working Together

The concept of improving communication skills of health professionals with various heart disease patient groups arose from our first steering group meeting in January 2002. The new format of British Cardiac Society, May 2003, enabled us to present the first very focussed 'how to' session on Communicating with Patients and Carers. I outlined Communication Theory – the person-centred approach, and Managing Interviews in which Difficulties may be Experienced. Shirley Law (Children's Heart Federation) with her post-Bristol experience, reminded us to listen to ourselves, language and attitudes as we talk to families devastated by congenital heart disease. Peter Houghton, Jarvik heart recipient (Transplant Support Network) made a great impact on the multi-disciplinary audience with 'The Sensitive Approach to the Dying' describing how to 'stay a person while you dissolve', 'feel marginalised', 'sympathy declining over time'. 'People are people through other people' (Akhosa proverb). Our other patient groups: CRY, Grown-up Congenital Heart

Association and Cardiomyopathy Association in particular are keen to contribute to future sessions.

### Medicine, the arts and the humanities<sup>2</sup>

'The greatest challenges for Society are all ones in which the arts and humanities and science and technology need each other .... education is about understanding and imagination as well as training and skills.<sup>3</sup> Medical Humanities is responding; the first conference of the UK Association for the Medical Humanities was held in Durham in July and New York hosts the Centre for Medical Humanities in October<sup>4</sup>. The British Medical Journal has championed the concept of POEMS, Patient Orientated Evidence that Matters, in recent times. A special edition of 26 July examined 'what is a good death?' and emphasised that doctors consistently over-estimated the time patients have left to live with cancer. Richard Chartres, the Bishop of London, in his President's Lecture for the Kings Fund in June drew attention to our society's inability to see life and death holistically: 'our failure to face our own fear of death is an important reason why we find it so difficult to help the dying and bereaved ....'.<sup>5</sup> The curative model of care does not fit for chronic conditions that may eventually lead to death. The recent publication of NICE's Clinical Guideline 5 on chronic heart failure includes section 1.5 Supporting Patients and Carers covering communication, prognosis, support, 1.6 on Anxiety and Depression and 1.7 on End of Life Issues. Sound grounding in the arts and humanities can enable an effectively critical human and ethical response.<sup>7</sup>

### Becoming Involved in Heart Care Partnership (UK)

We have several requests for input:

1. The British Association of Medical Managers needs patient representatives and I would invite anyone interested if they would like to submit a brief (one side A4 max) CV which I will forward (London & South East base).
2. Cardiovascular Disease' Specialist Library (CVDSL) External Reference Group would also like a representative from Heart Care Partnership. If you feel that either you or a member of your Association can see a developmental interest here (West Midlands base) please also let me know.
3. Eastern Hull Primary Care Trust is doing a pilot study providing Cardiology Patients with a telephone helpline which searches for information such as outstanding test results, out patient appointments and waiting list queries. There is little formal research in this area although it is my experience that patients find the most helpful route into the system. Departments are at different stages of development here. Please let me know of your experiences and/or suggestions and/or send direct to [tracey.kingdom@herch-tr.nhs.uk](mailto:tracey.kingdom@herch-tr.nhs.uk)

The Patient Conference kindly organised by the British Heart Foundation for 12 November 2003 at the Paragon Hotel, Birmingham I have suggested we might use up to 20 places. It is designed to help inform and empower individuals who have CHD although we have a wider brief. For further information or to register an interest in attending the conference please contact Jean Bircher, Patient Network Co-ordinator, [bircherj@bhf.org.uk](mailto:bircherj@bhf.org.uk)

I look forward to seeing a representative from invited associations on 18 September at the British Cardiac Society in Fitzroy Square.

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4. Centre for Medical Humanities.  
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Age Concern  
AICD Support Group (rational)  
British Cardiac Patients' Association  
British Heart Foundation Heart Support Groups Network  
Children's Heart Federation  
Cardiomyopathy Association  
CHD Collaborative  
Chest, Heart and Stroke Association  
Cardiac Risk in the Young  
Diabetes UK  
Expert Patients  
Grown-up Congenital Heart Association  
Heartlink  
Heart UK  
Marfan's Association  
Medical Technology Group  
National Heart Forum  
Patient Advisory and Liaison Service (PALS)  
Patient Expert Group (BCS)  
Pulmonary Hypertension Association  
QPDT/LIT/Network representation  
Sudden Adult Death Syndrome (SADS UK)  
Take Heart (independent support group representation)  
Transplant Support Network