



Patient Choice

Editorial: David Geldard

Patient choice is a topical issue in current disease management and seems to me to be in danger of being misunderstood by professionals, politicians and patients alike. It certainly places increased responsibility on all of these groups, but, if successfully developed, it should improve the quality of life for all. Choice is really about placing the patient as principal partner in his or her own health care and making sure that it is personal, it is fair and that it works.

The pioneering scheme of Patient Choice in Cardiac Surgery was successful not merely because there was a significant priming of extra funds, but it really did meet the above criteria.

There was a commitment to challenge Spanish customs and a chance for patients to reduce their waiting time by making an informed choice on their surgeon, venue and timing. The unusually independent role of the

Patient Care Advisers provided surgery patients with the knowledge and understanding to make informed decisions based on objective advice. The very positive response from patients together with increased efficiencies and dramatically reduced waiting lists enabled this choice approach to be rolled out to other disease areas with confidence.

It has been argued that Patient Choice is undermining respect for doctors and causing disillusion amongst clinicians. Hopefully this is ill founded. I see choice as an opportunity for patients to more fully understand their illness and to take more responsibility for its control and improvement.

For heart patients we are all familiar with the list of lifestyle factors that should stabilise or improve our condition. Stopping smoking, lower cholesterol, avoid smoky rooms, control body weight, reduce fat, sugar and salt intake, increase

fibre, increase exercise, check blood pressure, moderate alcohol intake, check for and control diabetes, and take medication as prescribed. What has been missed? We should all take an exam and walk a mile for every factor forgotten.

The choice is ours. Get more involved. Become more active in the management of your problem. Remember it's a partnership not a conflict – be nice to yourself and those who care for you. And every morning when you wake up, thank your lucky stars and make the most of the day – and many more to come.



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HCP (UK) is welcomed as an affiliated group of the British Cardiac Society at the BCS Annual Scientific Conference 2004

This year the British Cardiac Society Annual Scientific Conference was held in Manchester on 24-27 May. This year Heart Care Partnership (UK) held a two

hour session on Tuesday 25 May and co-produced a session on Wednesday 26 May with the British Association for Nursing in Cardiac Care (BANCC). HCP (UK) also

had a stand in the main exhibition on which member groups were represented. Here is an overview of presentations given by HCP (UK) over the two days.

HCP (UK) Session Tuesday 25 May: Interface of Heart Care Partnership (UK) with network patient and carer partnership

David Geldard

The National Service Framework proposed the formation of local networks of cardiac care. The pace to create a comprehensive patchwork across England and Wales will gather speed as CHD collaborative funding will be devolved to effective networks by April next year.

Evidence of real patient involvement and influence in each network, with patient representation on the board and evidence of patient driven redesign work, using patient surveys or discovery interviews will be required.

Patient and carer participation across the range of heart disease provision will become normal and this will require procedures for selection, training and assessment.

Speaker's biography

David Geldard spent most of his career as a prison education officer, at one time having responsibility for education, libraries and vo-

ational training. He retired in 1994 and, after a prolonged wait, underwent a six-graft CABG in spring of 1995.

As part of his rehabilitation he turned to cycling and participated in overseas fundraising expeditions for the British Heart Foundation to Israel in 1996 and Jordan in 1997.

In 1998 he was appointed to the Order of St Johns for first aid training and joined the Bury and Rochdale Health Authorities CHD Strategy Group, of which he later became Chair. David was later appointed to the Greater Manchester and Cheshire Cardiac Board in 2001,

A trustee of the Patient Choice cardiac surgery programme he joined the CHD national NSF team in 2003, the CHD Programme board in 2004 and chair elect for the HCP (UK) in 2003.

"HCP (UK) has an important role to play in improving communications with heart patients and their carers"

HCP (UK) Session Tuesday 25 May: How to communicate with patients and carers

Jane Flint

Good communication in health care improves health and social outcomes for patients, and clinician relationships and performance. A shared care relationship between an informed patient and trusted health professional should be the aim of clinical consultation.

The interview should engage, empathize, edu-

cate and enlist. Psychological theory and practice of a person-centred approach in a therapeutic relationship considers the 'core conditions' of acceptance, congruence and empathy. Communicating risks means that patients too have to learn to live with uncertainty. Decisions about risk are not technical,

but value decisions.

Every clinician has a professional responsibility to recognize which interviews they find difficult and to overcome their shortcomings. In dealing with adversity, clinicians should respond promptly. Palliative care and understanding the principles of 'a good death' need further development in cardiological practice.

Improving communications is a policy objective reverberating between every health care body and public consultation process. Most people express a stronger desire for responsiveness to them as individuals, alongside a desire for a more human approach where people feel listened to, valued and respected as individuals rather than simply diagnoses.

Patient and carer involvement in cardiac service developments is leading the way since Bristol and the National Service Framework for coronary heart disease:

NICE consultations, MINAP audit, CHI NSF reviews, QPDT, LIT, network (in part Collaborative facilitated), and Expert Patient development. Through the Fifth Joint Report on Cardiothoracic Services, impact on workforce is also approached. Heart Care Partnership, affiliated to British Cardiac Society, may now extend patient/carer influence over holistic cardiac care.*

Speaker's Biography

Jane Flint has been the lead consultant cardiologist for the Dudley Group of Hospitals since 1988. She was a founder member of the British Association for Cardiac Rehabilitation and the Heart Care Partnership (UK).

Jane has taken an active role in the work of the British Cardiac Society, including Women in Cardiology Working group.

** If you would like to view slides from this presentation please email: hcp@bcs.com*



HCP (UK) Session Tuesday 25 May: Do we cover all groups— Ante-natal concerns Susie Hutchinson

There have been many lessons learnt about patient and carer communication within the field of paediatric cardiac care over the last five years. The Bristol and Brompton enquiries and the Alderhey scandal have highlighted the need for improvements throughout the service.

As we look at the fields of Foetal diagnosis, Neonatal surgery, Childhood care and the transition of paediatric care to adult service it is now clearly apparent that user involvement in treatment decision making is essential as medical services grow.

From the adversity of the past many good practises have emerged. Minimum standards of care written in partnership with users. Direct charity referral from hospitals to ensure that families have a broader understanding of heart care. Involvement in treatment decisions by both the patient and their carers.

It is now important to disseminate the posi-

"From the adversity of the past many good practices have emerged"

tive work that has been developed, by the multidisciplinary teams within childhood care, to a broader group of clinicians ensuring that all user group are able to

benefit from the advances already made.

Speaker's Biography

Suzie Hutchinson has specialised in the care and support of families faced with a diagnosis of single ventricle congenital heart disease for the last twenty years.

Having trained at the Royal London and Great Ormond Street Hospitals she worked at the paediatric cardiac unit at Birmingham's Children's Hospital for 15 years. During this time she held the position of Cardiac Liaison Sister.

Her current position is Director to the national charity Little Hearts Matter. The charity offers support and information to families facing the diagnosis, treatment and lifestyle issues synony-

Joint Session Wednesday 26 May: What do we really, really want?- a patients perspective *Peter Diamond*

The answer to the question should be based on common sense - shouldn't it? We have something wrong with us. We want it diagnosed, identified and then cured. However, human nature plays a big role by making the procedure pleasant and easy or really, really

horrible!

Speaker's biography

Peter Diamond is Chairman of the Chester Heart Support Group and a trustee of the Heart Care Partnership (UK)

Joint Session Wednesday 26 May: The GUCH Service—Patient representatives perspective *Paul Willgoss*

Individuals born with congenital heart defects have, over the last 40 years, increasingly survived to adulthood. This new generation of patients presents a range of complex issues for medical services and other service providers.

This short talk looked at some of the issues that anyone can face in their day-to-day life, but from the perspective of an adult with a congenital heart defect.

The issues examined concentrated on the non-medical impacts of living with a congenital heart defect, such as interrupted schooling, the effects of not being able to take part in PE at school, difficulties in accessing financial services and the societal view of people with a congenital heart defect.

The talk also looked at how, by appropriately supporting an individual, nursing and medical

services can help give these individuals confidence in managing their conditions which can have a cascade effect in other areas of their lives.

Speaker's Biography

Paul Willgoss has been the Vice-Chair of the Grown Ups with Congenital Heart Defects Patients Association for the last 5 years.

Born with Fallots Teratology, Paul enjoys walking, drinking and eating with friends, though not always in that order.

"By supporting an individual nursing & medical services can give them confidence"

Next year the BCS Annual Scientific Conference will be held on 23-26 May 2004 at the G-Mex/MICC Manchester

Related Links

Grown-Up Congenital Heart Patients Association (GUCH) www.guch.org.uk

British Heart Foundation www.bhf.org.uk

Little Hearts Matter www.lhm.org.uk

Antenatal results and choices www.arc-uk.org

British Cardiac Society www.bcs.com

British Cardiac Patients Association www.bcpa.co.uk

Society and Heart Disease

Letter of POEMS: Patient Oriented Evidence that Matters

The British Cardiac Society Annual Scientific Conference opened with the St Cyres' Lecture entitled 'Society and Heart Disease: Determining Causes' given by Sir Michael Marmot. A classic study of Whitehall civil servants found the inverse relationship between health and social standing, the lower in the hierarchy the higher the coronary heart disease (CHD) risk, even in the non-poor. This gradient has persisted with time, despite the falling death rate, and the trend is more marked in women. While conventional risk factors account for just less than one-third of the social gradient in CHD the presence of low control over life a social disengagement are the most powerful explanatory factors for the social gradient of health. There is good evidence of socio-biological translation so that, for instance, 'protective' HDL cholesterol is higher in high-grade civil servants, and 'stress-related' cortisol is higher where there is high job demand and lower in lower grade civil servants with good social support. Overall, age, behaviour, biological fac-

tors and height explain 65% of the social gradient in CHD. Social epidemiologist, Roberto de Vogli, reminds us in his British Medical Journal book review of Marmot's recently published 'status syndrome'¹ that there are two competing policy recommendations to contain health disparities: should governments reduce inequality in material deprivation, or should they focus on reducing inequality in psychosocial disadvantage? More information is needed about the relative weights of these two factors. A philosophical narrative based medical text 'The Renewal of Generosity'² addresses both doctors and patients but its messages about compassion and generosity could apply to society in general. Three common sense but profound statements stand out in Frank's review: 'in order to lead a human life people need the generosity of their fellow humans'; 'to be generous first feel grateful'; and 'everyone who touches you affects your healing'.

These broad reflections help to place in context a the use of B-type natriuretic peptide (BNP)

measurement as a 'rule-out' test for patients with new symptoms suggestive of heart failure has been supported by the National Institute for Clinical Excellence (NICE) and European Society of Cardiology, preferably as part of a structured approach to the diagnosis of heart failure³. A much quoted study this year⁴ states that knowing the level of B-type natriuretic peptide during initial evaluation in the Emergency Department is associated with more rapid initiation of appropriate treatment, less need for hospitalisation and intensive care, a shorter length of stay and lower costs. The ability to present a good business case for its use in Emergency Departments is likely to determine how widespread its implementation. Patients may help to influence Commissioners through the local Cardiac Network Boards and their Clinical Advisory Groups.

It is currently estimated that there are 1.28 million prescriptions for warfarin for patients with the common arrhythmia atrial fibrillation (AF) in the UK. With 1% of the population

Letter of POEMS continued

having AF the potential financial implications to the NHS are enormous, yet the anticoagulant cost of 16 million if all patients were treated remains a small proportion of the overall direct costs including hospitalisation of £459 million in 2000. The total cost to the NHS per annum due to adverse events secondary to warfarin is estimation at £56 million. The new Ximelagatran, a reversible direct thrombin inhibitor is given as a standard dose and does not require anticoagulant monitoring⁵ so there may be potential savings but some monitoring of liver function may be required. A clinical and economic case may be made for Ximelagatran, pharmacogenetics may be useful to identify warfarin-resistant and over-sensitive patients for targeted safer anticoagulation. The concentration of fibrin D-dimer, a

measure of fibrin turnover, is elevated in some patients with AF and may be a useful marker of high stroke risk together with tissue plasminogen activator. The combination of risk stratification (using clinical and laboratory markers) and potentially the use of safer anticoagulants may result in many more patients with AF being appropriately treated.

Significant dialogue with patients and carers is needed to discuss all these issues. Cardiological services have pioneered the way for patients and carer involvement, so what other areas can Heart Care Partnership consider priorities for the future? To stimulate discussions at our AGM and joint meeting with a Cardiac Network Patient and Carer Partnership I put forward the concept of using action learning sets⁶ exemplified in care

pathway development and quality improvements. Lessons from the Titanic, scientific endeavours and the Yorkshire coal pits have informed the action learning set approach, demonstrating the all important principle – no-one knows everything and answers can be found everywhere. We badly need more common sense patient input to help rationalise and reduce the bureaucracy now attending research ethical committee approval. A balance must be found to ensure an appropriate degree of patient confidentiality without making it impossible to conduct research into questions with overall benefit to society⁷.

**Dr Jane Flint BSC MD FRCP
Consultant Cardiologist
Clinical Director, Black Country Cardiac Network
Trustee, HCP (UK)**

References/Further Reading

1. Marmot, M. (2004) *Status syndrome: How your social standing directly affects your health and life expectancy*. Bloomsbury
2. Frank, A.W. (2004) *The Renewal of Generosity: illness, medicine and how to live*. University of Chicago Press
3. Cowie, M.R (2004) *B-type Natriuretic peptide testing: where are we now?* Heart 90:725-6 Editorial
4. Mueller, C et al (2004) *Use of B-type natriuretic peptide in the evaluation and management of acute dyspnoea*. N. Engl. J. Med 350: 647-54
5. Rose, P (2004) *The real cost of Warfarin for patients with AF* Thrombosis 8,1,2
6. Lavery, S (2004) *Helping doctors to solve problems* BM J Career Focus 10 Aug, p59-60
7. Ward, H. J. Tet al (2004) *Obstacles to ... epidemiological research...UK general population* Academic Medicine Campaign BMJ 329: 277-9

Heart Care Partnership (UK) Annual General Meeting 2004

Agenda

1. Apologies for absence
2. Minutes of the last AGM
3. Matters arising
4. Progress report from Officers
 - British Cardiac Society Annual Scientific Conference (HCP (UK) and BANCC Sessions)
 - Administrative links., websites, guidelines for Treasurer
5. Membership
6. Election of Officers/Trustees
7. Future developments

**The second AGM of the Heart Care Partnership (UK) will be held on
Wednesday 15th September at 14.00-15.00 at the
Molineux Stadium, Wolverhampton**

An Invitation...

HCP (UK) Chair Eve Knight and Chair Elect David Geldard would like to invite all the Trustees and members of HCP (UK) to the Annual General Meeting. The meeting will be held during the Black Country Cardiac Network and HCP(UK) meeting sponsored by the CHD Collaborative (see page 8 for further details).

Black Country Cardiac Network/Heart Care Partnership (UK)

A Meeting of the Network Patient and Carer Partnership in conjunction with Heart Care Partnership (UK)

Sponsored by Black Country Cardiac Network and CHD Collaborative

To be held on Wednesday 15 September 2004
At Molineux Stadium Wolverhampton

Programme

10.00am	Registration and Coffee	
10.30am	Welcome and Introduction	Jane Flint
10.45am	Hearts Undergoing Support (HUGS) Dudley	Pam Cansdale
11.00am	Wolverhampton Aftercare Group	Ken Timmis
11.15am	Walsall Patient and Carer Partnership	Carol Reilly
11.30am	Patient involvement in cardiac services — and how the Network fits	Jane Flint
12.00pm	Patient perspective and HCP (UK)	David Geldard
12.30pm	Open discussion questions	
1.00-2.00pm	Lunch	
2.00-3.00pm	AGM—HCP (UK) (Posters and stands for those not attending)	Eve Knight, David Geldard, Officers, Trustees, Member Associations and Members
2.00-3.00pm	Coffee/Tea with An Exploration of the Interface with HCP (UK) (The way forward) What do patients want at local network and national levels	
4.00-4.15pm	Summary and Close	

For more information on this event please email: hcp@bcs.com or call 020 7383 3887

Future Events

Involving to Improve: Patient and Public Involvement in Cardiac Networks

This event will take place on Thursday 9 September at the NEC Birmingham. It will aim to support networks in improving their patient and public involvement strategies.

The day offers a full programme of keynote speakers and workshops.

Further details can be obtained by contacting the CHD Collaborative 0116 222 1414

A patient network meeting arranged by the **British Heart Foundation** will take place on 11 September in Leeds.

For more information contact the British Heart Foundation on 020 7935 0185

Does your organisation have an event or news item they would like to see included in the HCP (UK) newsletter or website?

If so please send details to
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c/o British Cardiac Society
9 Fitzroy Square
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Tel: 020 7383 3887
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Coming Soon...

Heart Care Partnership (UK) website at
www.bcs.com