



**Heart Care Partnership
(UK)**

JUNE 2010

NEWSLETTER

HCP UK are grateful for input to the Newsletter, please contact
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Affiliated to the British Cardiovascular Society

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FOREWORD



*Ken Timmis, President of
Heart Care Partnership UK*

Twenty years ago I suffered a heart attack and thus became involved in the cardiac arena. Such was my gratitude to those who looked after me that I resolved to serve those who suffer as I did to the best of my ability. Yet mine is not the only story of its kind. There are many across the length and breadth of the land who feel as I do.

I have been privileged to meet many such people and to be allowed to mix with many excellent clinicians who seek to serve them, especially since my elevation to the rank of Heart Care Partnership UK President. I have been able to express my views and the views of my fellow patients in forums I had never heard of twenty years ago.

There has been much progress also during that time in cardiac services. I think of the developments in the surgical field, the invention of Stents, Primary PCI and Rehabilitation in particular, and I look forward to future developments yet to be achieved.

The Trustees of Heart Care Partnership UK bring to the table a very wide range of expertise in all branches of cardiac services, both voluntary and professional, and this is the true strength of our organisation as is evidenced by the Who's Who publication that we produce. In the past year we have recruited new Trustees to complete the board and I feel that in future we shall co-opt even more experts to enhance the service we offer.

We now have full charity status and are preparing funding bids to enable our work to flourish. We need to increase our membership and organize gatherings to bring them together. We also need to spread knowledge of our existence across all support groups in the UK.

The first ten years of the National Service Framework for Coronary Heart Disease has ended and we have entered the second decade by including all forms of vascular disease. Although cardiac rehabilitation is successful in my own area of the Black Country, across the nation there is still much to be done. David Geldard MBE and I have recently been members of a

panel looking at the commissioning of Cardiac rehabilitation in an effort to encourage more uptake. I am hoping this will bear fruit.

Although I have not seen what articles follow in this newsletter, I am sure they will give a flavour of what we are about and where we are hoping to go. It only remains for me to thank my fellow Trustees for their endeavours and Lulu also, our Affiliates Co-ordinator, for her untiring work on our behalf.

Kenneth Timmis MBE JP LCIE

President's Report 2010

Since my last report we have at long last acquired charity status and I would wish to thank the officers of the BCS for their assistance in the process. Thanks too to Lulu Ho and her predecessors for the spadework involved.

Further highlights were to hear that Trudie Lobban and Paul Willgoss, both our Trustees and CEO of Arrhythmia Alliance and respected advocate of GUCH respectively, had received well earned MBEs in the Queen's honours list. Congratulations Trudie and Paul, you both deserve it.

We were all saddened at the last AGM, when we had to accept the resignation of Anne Jolly as Secretary. Anne had done a sterling job over the years of her tenure, keeping us in order and expanding our work in addition to running her own organisation. Anne continues to work with us as a Trustee and for that we are grateful. Fortunately in Carol Reilly, Black Country Network Manager, we have found a very worthy successor, which has softened the blow somewhat.

During the year two new members have joined our team, adding their expertise to our deliberations and service. Julie Wootton brings her paediatric and congenital expertise on children's heart problems as Chair of Trustees of Children's Heart Federation and Max Appeal. This will add a new dimension to our work.

Our second acquisition comes in the form of Dr. Felicity Astin. Felicity is a Senior Research Fellow in the School of Healthcare at the University of Leeds. She has a keen interest in raising awareness about the benefit of service user and carer involvement in teaching and research in cardiac care. She is leading funded research (in collaboration with Leeds Acute

Trust) to better understand people's experiences of cardiac interventions. Findings are used to inform service development and develop patient/carer centered information resources. She is currently part of NHS Improvement working group developing information for people recovering from primary angioplasty. We are very fortunate to have her services and contribution.

Our Past President, David Geldard MBE, continues to travel up and down the country for meeting after meeting, which leaves me breathless. He is specialising for the team in Cardiothoracic Surgery, leaving me to cope with the Cardiology side of our work, a split of activities which is proving advantageous to us both. We join forces in our efforts to improve Cardiac Rehabilitation uptake across the nation, both of us having been drafted onto the reference group to inform the development of the cardiac rehabilitation (CR) Commissioning Pack, chaired by Professor Patrick Doherty, Chair of Rehabilitation, York St John University. I could fill this report with the multitude of activities undertaken by David, but I hope he will forgive me if I resist the temptation as there is so much else to report.

I have also joined a research group, The United Kingdom Transcatheter Aortic Valve Implementation (UK TAVI) Trial, chaired by Dr. William D Toff, Senior Lecturer in Cardiology & Director Leicester Clinical Trials Unit at the University of Leicester. The research project is to assess the clinical and cost effectiveness of TAVI in patients with severe symptomatic aortic stenosis who are at high operative risk or unsuitable for conventional aortic valve replacement (AVR).

I was privileged last year to be asked by the British Heart Foundation to address a gathering of MPs and Lords in the House of Commons on behalf of heart patients at the Cardio & Vascular Coalition launch of "Destination 2020", a plan for cardio and vascular health for the next ten years. Also in February of this year I was joined by David Geldard, Anne Jolly and Suzie Hutchinson in Westminster, when the BHF organized a pre-election lobby of MPs, hoping to get Heart Health included in election manifestos.

Through our new Secretary, Carol Reilly, we are beginning to embrace stroke in our curriculum, which adds vascular to our remit. She attended the House of Commons for the launch of a new report from the Stroke Association, "Getting Better: Improving Stroke Services across the UK". It consists of case studies highlighting best practice, issues and challenges to drive forward stroke care (www.stroke.org.uk). In attendance were Andrew

Lansley CBE MP, Shadow Health Secretary and Chair of the All Party Parliamentary Group on Stroke, Ann Keen MP, Parliamentary Under Secretary of State for Health, MPs and stroke representatives, so the “Stroke Voice” is being heard at the highest level.

I never hear the name, Paul Willgoss, without thinking of GUCH for which he gives so much of his time. The service provided to adults with congenital heart disease is in the process of being reviewed and developed, based on the NHS commissioning guide. The Grown Up Congenital Heart Patient Association has been working regionally and nationally to ensure that these processes genuinely reflect the needs of a growing patient base and that they provide a seamless service to which children covered by paediatric services can subscribe. Together with Suzie Hutchinson and Julie Wootton he has been working as part of the user voice within Congenital Cardiac service provision on the safe and sustainable review of England’s paediatric congenital heart surgical care provision which will lead to the finalization of antenatal and surgical congenital heart disease care standards and a re-organisation of the national service provision. The work has included input on surgical pathway standards, antenatal care and diagnosis standards and sub specialization of congenital surgery proposals.

Dr Jane Flint continues to champion Women’s Heart Health issues, incorporating the outcome of the Euroheart Work Package 6: ‘Red Alert – Women and Cardiovascular Research in Europe’ in our final full BCS Report and Recommendations; and also Cardiac Rehabilitation Development this year for presentation at the National Cardiac Conference 2010.

David Geldard has at our request added sexual activity concerns of heart patients to his remit. Liz Clark has been a patient representative on the NICE Chest Pain Guideline which is due for publication in March. She is now on the Angina Guideline. Trudie Lobban continues to be a tireless worker for Arrhythmia Alliance and Peter Diamond continues to work with THRIVE, Suzie Hutchinson, our Treasurer, with Little Hearts Matter and Anne Jolly with SADS UK. All in all we have a very active team for which I, as their President, am truly grateful.

Ken Timmis MBE JP LCIE

ACHIEVEMENTS

Helen Williams wins GHP/UKCPA TEVA Leadership Award 2010

We are very pleased to announce that Helen Williams, the South London Cardiac Stroke Network's prescribing advisor and pharmacy team leader for cardiac services at King's College Hospital NHS Trust, has won the Guild of Healthcare Pharmacists (GHP) and the United Kingdom Clinical Pharmacy Association (UKCPA) TEVA Leadership Award 2010 for her submission, '*Developing the role of a pharmacist in a managed clinical network*'.

The award was presented to her 14 May, during the GHP/UKCPA 6th Joint National Conference, [*Pharmacy's future: Leadership through partnership*](#) in Leeds. Helen presented her work during the award presentation session.

NEW APPOINTMENTS

We welcome Felicity Astin from Leeds University as a new Trustee to HCP UK



Felicity has worked as a clinical nurse specialist, lecturer and researcher during her career.

She is currently a Senior Research Fellow in the School of Healthcare at Leeds University. She works closely with NHS partners, patients and carers with the shared goal of improving cardiac care services and reducing health inequalities. She has successfully attracted funding from the National Institute of Health Research to support collaborative projects.

Felicity has a particular interest in angioplasty and has conducted research both in Australia and UK to explore

patients' recovery after this treatment. This work has informed the development of 'patient centred' health information resources for use in clinical practice. More recently Felicity joined an NHS Improvement-Heart working group. This group is developing national guidance about health information provision to assist clinicians developing primary angioplasty services.

Felicity also plays an active role in the education of undergraduate and post graduate students at the University of Leeds. She uses findings from project work to give students a 'real' insight into patients' and carers' experiences of cardiac services. As well as being on the Board of Trustees for HCP UK she also serves on the Education Committee of the Council of Cardiovascular Nurses and Allied Professionals with the remit of curriculum development for post-registration cardiac nurses in Europe. More locally she is involved on a working group redesigning cardiac services in Leeds.

SOUTH ASIAN HEALTH FOUNDATION (SAHF)

The South Asian Health Foundation have developed a DVD on CHD in south Asians and also one on Diabetes in south Asians, both of which have been well received and are available from SAHF at info@sahf.org.uk.

The website has details of all SAHF activities but in particular, some to highlight are:

1. Community based events on CVD and Diabetes which the charity is willing to help organise and deliver (see www.sahf.org.uk/uploads/docs/newsdocs/12.pdf for an example of a recent event in Glasgow).

2. They also have a statement on the harms of smokeless tobacco, use of which is common in some ethnic groups and contributes to health inequalities.

www.sahf.org.uk/uploads/docs/newsdocs/11.pdf

3. A synopsis of obesity and ethnicity is also available at www.sahf.org.uk/news.aspx?id=16 and they held an International conference on Obesity and Diabetes, an excellent meeting for all healthcare professionals

Kiran Patel, Chair of trustees

DAVID H GELDARD MBE

The NICE Guideline Development Group for Non ST Elevation MI, has been working for around eighteen months under the direction of Prof John Camm and Dr Huon Gray, has had its' efforts recognised with the Guideline launch. NICE have asked me to provide a photo interview of the patient perspective for the British Medical Journal's on-line summary of this guidance.

In December 2009, at the request of the Department of Health, Ken Timmis and I were asked to participate in an IPSOS MORI survey to assess the impact of ten years of the CHD NSF. This review is now concluded and by all accounts, and not unexpectedly, it has been judged an extraordinary success. In my view, the quality of leadership has been the most significant factor in this achievement.

The National Campaign for Cardiac Rehabilitation, steered by the British Heart Foundation, held a successful Parliamentary Lobby on the 3rd of February. David Houghton, Danny Jenkins, Ken Timmis and I participated.

The Society for Cardiothoracic Surgery in Great Britain and Ireland held its Annual Meeting in Liverpool in early March. We arranged a Patients' Forum on the Monday and involved patient representatives from the Greater Manchester and Cheshire, Merseyside, Lancashire and Cumbria, West Yorkshire, and Black Country Cardiovascular Network, together with the Roy Castle Lung Cancer Foundation. This built on our pilot efforts at last year's meeting in Bournemouth, we were strongly supported by the cardiac surgical nurses and it proved to be a very worthwhile day. In particular, the patient representatives were most impressed that Professor Sir Bruce Keogh, the Medical Director of the National Health Service, visited our Forum, addressed the group and spent nearly half an hour with us responding to questions and queries.

Ken Timmis and I have been asked by the Department of Health to join a select reference group to inform the development of a cardiac rehabilitation (CR) Commissioning Pack to be rolled out across England and Wales by the end of the year. This is the major piece of unfinished business of the National Service Framework and will be hugely welcomed by patient representatives and patients everywhere. Our Report will be submitted this summer.

In March, Professor Jahingari asked me to speak about cardiac rehabilitation to a combined group of cardiologists, cardiac surgeons, nurses and supporting colleagues at St George's.

The NHS Heart Improvement Conference 2010 held in London on 24th March, was a fitting event to recognise the achievements during ten years of the National Service Framework for Heart Disease. It was good to be invited and good to see the triumvirate of Professor Roger Boyle, Dr Mark Dancy and Professor Sir Bruce Keogh looking very much the same as they did ten years ago. Many more of us patients are still around to bear witness to that fact, and in no small measure the fact that we are still here is down to their leadership.

The Trans Pennine Cycling Club held their X11th Annual "Over the Edge" sponsored cycle ride in aid of the British Heart Foundation took place on May 16th, Hollingworth Lake, Littleborough. Three routes, Bronze 23 miles, Silver 29 miles and Gold 52 miles concluding with the ascent of Cragg Vale, England's longest continual up-hill climb of just over six miles.

David Geldard, HCP UK Past President

HEARING THE VOICE

The real partnership through which we improve care pathways for patients with heart disease is a great achievement particularly appreciated after reading Christine Hogg's "Citizens, Consumers & The NHS: Capturing Voices" (2009) as we put together our Core Funding application. No change in Public and Patient Involvement strategy can now detract from the major progress patients and carers have made, acknowledged by health professionals, to be at the centre of service decisions. David Geldard and Ken Timmis have recently been active with the Cardiac Reference Group for the Department of Health's first Commissioning Pack devoted to Cardiac Rehabilitation, and not long beforehand with the NICE Guideline Group for Acute Coronary Syndrome just published in March 2010. The Cardiac Networks have nearly all revisited their Cardiac Rehabilitation pathway following Primary and other earlier Coronary Intervention (P/PCI). We have been instrumental in encouraging a NHS Improvement Heart working group to look at Patient Information specifically for post PPCI patients who may perceive the treatment as providing them with a 'fix and cure'. Felicity Astin and I will take the opportunity with our Networks to instigate a specific information leaflet with HCP UK support.

The working group has emphasised how information for these patients must be provided from the very earliest opportunity.

As we listen out for the voice of our members and member associations the development of communication methods advances, and not just technologically, but in the presentation of the genuine recognition that all participants in any life situation may see the issues very differently. Peter Lapsley's occasional "A Patient's Journey" series in the British Medical Journal has captured poignant moments, patient impressions and life course, with alongside "Consultation" presentations and outcomes accounted by the health professionals involved. Liana Daley died a few weeks before publication on the 10th April 2010 of her reflections on her cardiomyopathy, her Cardiologist's and Psychiatrist's professional clinical accounts within highlighted text boxes. Liana emphasised how she wished she had received consistent support from the earliest stage of her illness and admission. Her Psychiatrist expressed surprise at the self –concept of this dignified, beautiful and clearly expressing woman as "ugly" with her stroke-paralysed hand. The communication "gulf" can seem enormous.

Graphic stories are proving a popular, novel and creative new cultural trend in learning about illness, both in medical education and patient care (Michael J Green & Kimberly R Myers, British Medical Journal, 340, 574-577, 13 March 2010). Both the text of spoken words, and the subtext of what thoughts are not actually spoken, can be amusingly represented in strip cartoon format, illustrating that what we say is not always what we mean. The medium is particularly appropriate for educating the diversity of patients, when verbal communication may be challenging. Visual understanding is considered intuitive in ways that verbal understanding may not be, and there is research in educational psychology to support the combined use in explanation, adding new knowledge, and in recall. We are therefore making use of graphics in our out-patient consultation leaflet reminding both patients and health professionals how to make the most of the consultation process and communication.

The key to a successful clinical interaction is to always place the patient's context at the centre. *BMA News* recently ran a writing competition with the theme 'Conflict of Interest'; would I had found the time to run with and further elaborate the principled approach that this may always be avoided if patient and carer, the lifetime risk, and equity of access, are always the priority. The Marmot review: "Fair Society: Healthy Lives" (February 2010) should be made to impact on how we run Education, Health and Social Care. The recent change of

government and new approach to financial constraint is likely to reduce the rate of change. A Patient-Led NHS is however at the top of the priority list just disseminated this week by the new coalition government so there is hope.

My Humanities' exploration this year has come across the Hippocrates Prize for Poetry in Medicine, run jointly by the University of Warwick Medical School and Writing Programme (Michael Hulse & Donald Singer, April 2010). We are reminded how often scientific writing was done in verse in the ancient world. There were 1600 entries from 31 countries for the first year of the competition. Both NHS staff and open category 'literary folk', including patients and carers of course, were invited to submit work. I have begun to prepare a poem for next year.

E Jane Flint BSc MD FRCP

National Clinical Lead for Cardiac Rehabilitation and HCP UK Trustee

SALFORD HEARTCARE

For heart patients and their carers and families

Celebrating our 23rd Anniversary Year 1987 – 2010



Barbara with Jim Collins, Chairman of Salford Heart Care Support group and Elizabeth Charnley, Volunteer Co-ordinator for Salford Sidekicks.

Barbara Keeley recently met Elizabeth Charnley and Jim Collins at a British Heart Foundation event in Westminster to pledge her support to tackle heart and circulatory disease in Salford. Jim is Chairman of the Salford Heart Care Support Group and Elizabeth is the Volunteer Co-ordinator for Salford Sidekicks, which is part of Salford Heart Care.

Barbara, Elizabeth and Jim discussed the work that Salford Heart Care Support does to help local people with heart disease, as well as their families and carers.

Following this, Barbara dropped in to a Red Day held by Salford Heart Care at their regular fortnightly meeting in Eccles. The Red Day was held to celebrate National Heart Month and many group members came dressed in red, with a prize for the most outstanding red outfit. Jim and other members told Barbara about all the different activities that members can take part in including dance, exercise and weekly walks.



Barbara with (left) Jim Collins Chairman of Salford Heart Care Support group and (right) Fred Gorvett at the Red Day in Eccles.

Barbara said:

“Salford has a high rate of heart disease but our local cardiac consultants and rehabilitation services are working hard to bring this down. I know that Salford Heart Care Support Group is doing a great job of supporting local people to recover after illness.

I was pleased to attend the Red Day in Eccles and it is good to know of the support and activities available at the Salford Heart Care Support Group. I’m pledging my

support to tackle heart and circulatory disease at the next General Election and beyond.”

For more information on the work of this Support Group, please phone the office on 0161 707 7402, or e-mail Salfordheartcare@onetel.com

SOUTH LONDON CARDIAC AND STROKE NETWORK

Earlier this year, the South East London and South West London Cardiac and Stroke Networks (SLCSN) joined together under the direction of Lucy Grothier. The networks share the same mission and vision – to improve cardiac and stroke care for all residents of South London.

Cardiac and stroke networks create an infrastructure of alignment along the patient pathway, from prevention to rehabilitation, between patients and those that treat them. In this role, the SLCSN helps South London healthcare organisations deliver measurable, evidence-based high quality care with financially viable productivity.

New Website

We've launched a new Web site, www.slcsn.nhs.uk, which contains information for both patients and clinicians: guidelines and best practice documents, upcoming events, information on our projects and links to related organisations and health news and more.

Patient events



A few months ago, the SLCSN hosted two cardiac patient events, one in South East London, the other in South West London. The purpose of the event was to better understand patient and public views on cardiac care within the NHS and to identify areas of improvement as determined by those who would know best – the people who have received that care.

Four key areas of improvement were identified by our participants:

- Pathways
- Prevention and rehabilitation
- Communication
- Primary care

We continue to work with our partner healthcare organisations in these areas to achieve high quality care with a positive patient experience. Read the full event summary on our website.

People Bank



Input from patients, the public, clinicians and carers is essential to improving cardiac and stroke care. The SLCSN has developed a [People Bank](#) to inform those interested of future participation events. There is no obligation to join all of the events; registrants can choose the ones they wish – surveys, interviews, focus groups, etc.

To register with the SLCSN People Bank, simply e-mail your name and contact details to the People Bank e-mail address: People@slcsn.nhs.uk. An online form is also available on our Web site, www.slcsn.nhs.uk/involved.html.

ARRHYTHMIA ALLIANCE, THE HEART RHYTHM CHARITY

Now in its seventh year, Arrhythmia Awareness Week (AAAW) has been instrumental in helping to highlight heart rhythm disorders and work towards improving the diagnosis and treatment of this once largely overlooked area.

AAAW 2010, from June 7th-13th intends to raise public and medical awareness of the pulse as a means of identifying potential cardiac arrhythmias, with a 'Know Your Pulse' campaign. The long term goal is for routine pulse checks to be performed in GP surgeries. For information on the 'Know Your Pulse' initiative, visit www.knowyourpulse.org

This year's events for AAW will include regional pulse check sessions where professionals educate members of the public in this simple health check procedure. A-A will also use the week to gather data surrounding the efficacy of pulse checks.

The 'Know Your Pulse' campaign also reflects the Department of Health's focus on Atrial Fibrillation as a leading cause of stroke by promoting early and effective screening. Examples of best practice are available to view at www.atrialfibrillation.org.uk. As part of this, A-A is advocating to Primary Care Trusts that they include pulse checks in the NHS cardiovascular Health Checks and in flu clinics.

A-A and AFA have also developed supporting resources for professionals and areas looking to incorporate manual pulse checks into their practice. These include toolkits, publications, and website materials which can be viewed, downloaded and ordered through the A-A, AFA and 'Know Your Pulse' websites.

Over the next few months, A-A will continue to source data relating to the benefits and costs associated with performing pulse screening. If you would like to submit evidence or require further information about the 'Know Your Pulse' campaign please contact Joanna Fearnley at joanna@heartrhythmcharity.org.uk or 01789 451 823.

JOINING UP THE DOTS....OUR EXPERIENCE

Introduction & Background

In 2008 the Department of Health (DoH) released the long awaited End of Life Care Strategy (DoH, 2008). At the core of this comprehensive framework is the tenet that palliative and end of life care is available across all settings on the basis of need, not diagnosis, thereby incorporating conditions other than cancer including Heart Disease. St Joseph's Hospice (STJH) is set in the heart of East London (EL), an area well known to be made up of many layers of diversity. As an organisation we are deeply committed to a participatory approach to the development and provision of palliative care services by engaging with the citizens and communities it serves as described by a number of key authors (Kellehear, 1999; Weaver, 2004; Scott, 1992).

In 2006 STJH launched a 5 year strategy, one objective of which is concerned with seeking the community's views regarding their needs and preferences regarding end of life care through consultation. Other objectives related to the extension of care beyond cancer to conditions such as heart failure (in light of its prevalence and impact on patients and carers) and development of services that are both acceptable and accessible to communities previously underrepresented in the profile of patients using the service. These included individual and teams from local ethnic minorities.

Establishing a patient-led pathway

In July 2007 funding was secured to undertake a multidisciplinary/cross sector project led by STJH. In particular, it sought to identify the needs and preferences of individuals from the Bangladeshi and Somali communities within Tower Hamlets, by exploring their experience of heart failure, their expectations of treatment, their requirements of care and opportunities for its improvement. This gave particular attention to care at the end of life and palliative care requirements within. Whilst pathways were already in use, these were based on professionals' views of appropriate care rather than the values and perceptions of members of these communities derived from their culture and ethnicity.

A project team (senior clinicians from primary, secondary, hospice care and staff from a community development organisation – Social Action for Health), met regularly over a period of 2 years to initiate and complete the project, monitor progress and disseminate findings. Specifically, Social Action for Health, via a model of empowerment around health improvement, used local ‘Health Guides’ to facilitate engagement with a wide variety of community members whose comments were fed back to the team. This participatory approach draws on the principles of Health Promoting Palliative Care as described by Kellehear (1999) which stresses the value of engagement of local citizens in planning new palliative services.

A new pathway was established as a result which highlighted the importance of:

- opportunities for advance care planning for patients as their disease progressed;
- clarity regarding the role of specialist palliative care and appropriate others involved in the pathway;
- empowerment and interest in further engagement for both users and staff; and,
- new partnerships with users and other professionals on the part of STJH.

Making the pathway operational

To strengthen the use of this pathway an educational event was held at St Joseph’s drawing together health professionals and members of the voluntary sector promoting this work. This pathway went on to receive a national award (Specialist category of the NHS Involvement to Impact Award).

Leading on from this, STJH has secured further funding enabling the appointment to the hospice of a part time Heart Failure Specialist Nurse who is working to increase awareness of heart failure and its accompanying issues in relation to end of life care. Information on heart failure is now readily available in each of the departments and wards throughout the hospice with staff having access to the nurse for individual advice and support. St Joseph’s have also engaged the services of the Consultant Nurse for heart failure from their local Trust, Barts and The London NHS Trust, who is working in collaboration with STJH’s own Nurse Consultant to strengthen the links between both services. Due to this collaboration there is now joint heart failure service and palliative care clinics being held, a Strategy for the Development of Support for People at the End-of-Life with Cardiac Failure is being developed along with

guidelines for staff regarding the care of patients who are reaching the end of life, who have implantable Cardioverter defibrillators.

The pathway, whilst continuing to inform service development, has also drawn attention to a number of key issues such as where patients with NYHA Class III – IV are currently being cared for and by whom? An audit of local services was also undertaken which highlighted there was a gap of information regarding heart failure-palliative care services for a majority of patients. Subsequently the outcome of the audit has provided a focus for our future work.

Future work planned

We plan to continue to develop our services for heart failure patients and collaborate with our local external colleagues. Our plans over the next year include:

- Creating continuity between hospital and community teams (heart failure, palliative care and the generalists e.g. district nurses) to ensure patients and carers know who they can contact and why
- Promoting public education – expanding our work with organisations and considering how we can best serve the interests and needs of our local communities. We would like to highlight how we can help in a multitude of ways and hopefully take away any fears that people may have about the hospice
- Considering advance care planning – this is about giving people the opportunity to express their personal wishes and beliefs that are then documented and also work towards planning for their future care in the event that they may be too unwell to do so at a later date. We would like to ensure health care professionals are ready to meet this challenge and provide appropriate education and support for them.
- Widening the education programme that we have begun, to include all of our local boroughs. This may include tours of the hospice for health care professionals so that they are able to tell patients about the facilities we can offer.

Reflections

The work undertaken has afforded us an opportunity to consider the value of partnership working and how important it is to involve and empower local communities, listening to patient preferences. This has allowed us to embark on the pathway work with a clear understanding of local need and how we can best serve our communities.

Collaborative working has also enabled us to engage with other local professionals and share learning experiences; this can mean being honest about both our strengths and learning needs within the partnership to optimise patient outcomes. Openness, flexibility and continued public engagement will continue to be vital in order to advance patient focused palliative care services in the future.

Jane Butler: Nurse Consultant in Heart Failure, Barts & the London Trust

Deebs Canning: Lecturer, St Joseph's Hospice & City University

Diane Lavery: Nurse Consultant, St Joseph's Hospice

Heather Richardson: Clinical Director

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Weaver, A. (2004) *Family Health Promotion during Life-Threatening Illness and at the End of Life.* In: P.J. Bomar (Ed.) *Promoting Health in Families*, 3rd Ed., Philadelphia: Elsevier.

FORTHCOMING EVENTS

British Cardiovascular Society Conference

7th – 9th June 2010

Manchester Central

www.bcs.com

Arrhythmia Awareness Week (AAAW)

7th – 13th June 2010

Heart Rhythm Congress (HRC)

3rd – 6th October 2010

Hilton Birmingham Metropole

www.hearhythmcongress.com



SADS UK

Heart to Heart Conference

Education and information to help save lives

Saturday October 23rd 2010

Royal College of Pathologists

2 Carlton House Terrace, London SW1Y 5AF

The cardiac charity SADS UK is holding their Heart to Heart Conference to educate and inspire attendees who may come into contact with families and individuals living with inherited cardiac conditions or who may have been affected by a Sudden Arrhythmic Death (SAD).

5th UK Stroke Forum

30th November – 2nd December 2010

Scottish Exhibition & Conference Centre (SECC) Glasgow

www.ukstrokeforum.org.uk



APPLICATION TO BECOME A MEMBER OF THE HEART CARE PARTNERSHIP UK

AFFILIATED TO THE BRITISH CARDIOVASCULAR SOCIETY

Please return to: HCPUK, 9 Fitzroy Square, London, W1T 5HW

REPRESENTATIVE NAME:

ADDRESS:

TELEPHONE NO:

EMAIL ADDRESS:

A BRIEF OVERVIEW OF YOUR ORGANISATION'S WORK:

MEMBERS OF THE HEART CARE PARTNERSHIP WILL RECEIVE INFORMATION ON MEETINGS, TRAINING COURSES AND EDUCATION AND INFORMATION SERVICES

- Please tick this box if you are happy for your information to be given to the British Cardiovascular Society for use when sending information on cardiac and stroke related issues

**MEMBERSHIP OF THE HEART CARE PARTNERSHIP UK IS
FREE TO USERS**