National Council for Palliative Care (NCPC) Response

All-Party Parliamentary Groups (APPG) on Heart Disease, Stroke, Kidney and Diabetes Inquiry: Gathering evidence for joint report recommending key priorities for the Cardiovascular Disease Outcomes Strategy

18th May 2012

Our key recommendation

We urge the APPGs to recommend in its report that palliative and end of life care be included as one of the key priorities for the Cardiovascular Disease Outcomes Strategy (CVDOS). This area of care and support is essential to people with cardiovascular disease and their carers, but too often overlooked. The significant amount of work that has already been undertaken in this area, including the national End of Life Care strategy (2008), End of Life Care in Heart Failure – a framework for implementation (2010) and NICE End of life care Quality Standard (2011) must be reflected and taken forward in the CVDOS and implementation plans.

This message will be reflected in our oral evidence on 12 June 2012, when we also hope to be able to develop some of the themes set out below.

Our full response

We welcome the opportunity to comment on the All-Party Parliamentary Groups on Heart Disease, Stroke, Kidney and Diabetes’ joint report outlining key priorities for the Cardiovascular Disease Outcomes Strategy (CVDOS). NCPC is the umbrella charity for all those involved in commissioning, providing and using palliative, end of life and hospice care in England, Wales and Northern Ireland.

We hope you find our response useful and adopt our key recommendation that ensuring people with cardiovascular disease can access palliative and end of life care when necessary is included as one of the key priorities for the Cardiovascular Disease Outcomes Strategy (CVDOS).
Key facts

- More people die with cardiovascular disease than any other set of conditions: it is an ‘underlying’ or ‘mentioned’ cause in 45% of all deaths in England.¹
- Heart failure affects at least 1% of people in the UK, increasing steeply with age, and is projected to rise with improved survival rates and an ageing population. ²
- Most people would prefer not to die in hospital, but at home or in their care home. In reality, 57% of people with cardiovascular disease die in hospital. ³
- Conversations focus largely on disease management, end of life care is rarely discussed with people with heart failure and clinicians are often unconfident in discussing this.⁴
- Of people accessing specialist palliative care services 18.3% have a primary diagnosis of heart failure or other heart or circulatory condition (including stroke) and 4.5% have chronic renal failure.⁵
- The latest National Heart Failure Audit reported that referral to palliative care upon discharge from hospital was “very low” with less than 4% recorded as being referred to these services.⁶
- People who die from cardiovascular disease are less likely to report that community services worked well together than those dying from other conditions.⁷
- Cardiovascular disease accounts for around 17%, and stroke 12%, of emergency admissions lasting 8 or more days and ending in death. Reducing the number of unnecessary hospital admissions at the end of life is a QIPP (Quality Innovation Productivity Prevention) priority.⁸

Why is palliative and end of life care so important?

The fact that the end-stage of a cardiovascular condition can be hard to determine should not be used as a reason to avoid talking about and planning for the future including end of life care. People with cardiovascular disease will die, and many of them will wish to discuss and think about this stage of their lives. Services and professionals have a responsibility to support them in this.

The unpredictability of the disease trajectory can often restrict choice of where a person is cared for and dies⁹ but this can be changed through early planning. Advance care planning can help ensure that people with cardiovascular conditions get the care they need, in a setting which they chose, and, ultimately, experience a good death. Indeed one of the key recommendations for commissioners in the End of life care in heart failure – a framework for implementation (2010) was that ‘advance care planning should be endorsed’²⁰. This needs to be in conjunction with good service planning, so that palliative and end of life care services are available locally to meet this need.

Advance care planning is not only vital to ensuring that people are cared for and die in the setting which they chose, but also to ensure that devices, such as implantable cardioverter
defibrillators (ICDs), are discussed and deactivated before death\textsuperscript{x}. Active ICDs can cause shocks at the end of life which can be very painful for the person and upsetting for those around them. Careful planning can ensure that deactivation of devices is handled correctly and sensitively, and can make the end stages of life much more manageable for people with heart conditions and their families. NCPC’s Heart Failure Group has found that specialist palliative care services are not uniformly equipped to deactivate devices, and want help in this area. Previous work of the group has found that good practice usually comes about through partnership working between heart failure nurses and specialist palliative care, links which are slowly strengthening.\textsuperscript{xii}

People with cardiovascular disease often have multiple conditions that require a range of services, which should be coordinated around the person’s needs and wishes. However, with only 6% of people with heart failure discharged from hospital being referred for palliative care, many people are experiencing poor symptom control, lack of psychological support and a lack of open and honest communication with professionals\textsuperscript{xiii}. Early, honest discussions and access to high-quality symptom control can ensure that the final stages of life for someone with cardiovascular disease are made as manageable and comfortable as possible.

Finally, it is important to remember that palliative care is of benefit \textit{from diagnosis through to the end of life}. This must be reflected in the CVDOS, as it would be a mistake (often made) to think of palliative and end of life care as an ‘add on’ or something that comes at the end of a person’s journey only. For people who experience a stroke or those who develop dementia in addition to a cardiovascular condition, early planning before capacity or the ability to communicate ones wishes is lost, is absolutely essential.

Building on what has already been done

The Terms of Reference state that the CVDOS will be written with reference to published frameworks and guidance. The following documents should be referenced in relation to palliative and end of life care:

- The NHS Outcomes Framework contains the outcome ‘improving the experience of care for people at the end of their lives’ with an indicator being derived from a national survey of bereaved carers. This survey will be able to track the experiences of end of life care in cardiovascular disease, amongst other conditions. [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_131700](www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_131700)
- National Council for Palliative Care, \textit{Focus on Heart Failure: A national survey of heart failure nurses and their involvement with palliative care services} (2006) and
Strengthening the relationship between heart failure nurses & specialist palliative care: Results from two national surveys – 2005/2010 (2011). A number of locally developed referral guidelines are also available at www.ncpc.org.uk/page/HFNS-Survey

- British Heart Foundation, *An everyday guide to living with heart failure* (updated in January 2012 to include revised pages on palliative and end of life care which NCPC helped to write) www.bhf.org.uk/publications/view-publication.aspx?ps=1001793


- A wealth of data and profiles can be found on the National End of Life Care Intelligence Network website www.endoflifecare-intelligence.org.uk

- The inquiry has expressed interest in ways of measuring CVDOS outcomes, for end of life care measurement see www.nice.org.uk/guidance/qualitystandards/endoflifecare/MeasuringTheQualityStatements.jsp

- The Key Performance Indicator for the QIPP end of life workstream is the proportion of deaths in usual place of residence. This

NCPC has eight groups of professionals and people with personal experience which drive and inform our policy and campaigning work, publications and activities. One of these groups specifically focuses on improving palliative and end of life care for people with heart failure. Its membership is:

- Dr James Beattie, Consultant Cardiologist, Birmingham Heartlands Hospital (Chair)
- Dr John Baxter, Consultant Geriatrician, Department of Care of the Elderly, Sunderland Royal Hospital
- Mubeen Bhutta, Policy Manager, British Heart Foundation
- Jane Butler, Consultant Nurse - Heart Failure, Barts & The London NHS Trust
- Simon Chapman, Director of Policy & Parliamentary Affairs, NCPC
- Alice Fuller, Policy & Parliamentary Affairs Lead, NCPC
- Dr Miriam Johnson, Reader in Palliative Medicine, Hull York Medical School & Honorary Consultant, St Catherine’s Hospice, Scarborough
- Dr Mike Knapton, Associate Medical Director, Prevention & Care, British Heart Foundation
- Annie MacCallum, Professional Lead for Specialist Services, NHS Gloucestershire
• Alice Rigby, Policy & Events Officer, NCPC
• Karen Sweeney, Programme Lead for the Healthcare Professionals Programme, British Heart Foundation

The Heart Failure Group has produced and contributed to many policy documents, conferences and surveys since its formation in 2005, as outlined in the Appendix below.

Other cardiovascular diseases

Our response has primarily focussed on heart failure, as this is the expertise of our group. However NCPC promotes palliative and end of life care for people with all conditions. Publications related to other cardiovascular diseases will need to be referenced by the CVDOS, such as:

• *End of Life Care in Advanced Kidney Disease: A Framework for Implementation* (2012)
• NHS Diabetes, *Commissioning for Diabetes End of Life Care Services* (2009)

See also:

• NCPC, *Multiple Conditions: Multiple Challenges - Exploring Palliative and End of Life Care for Older People with Multiple Conditions* (2008)

Further information

We’d be please to provide more information as needed. Our key messages will be echoed in our oral evidence on 12 June 2012, provided by Dr Jim Beattie and Simon Chapman.

Appendix

NCPC’s Heart Failure Group timeline:

<table>
<thead>
<tr>
<th>Date</th>
<th>Output</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feb 2005</td>
<td>Circulatory &amp; Respiratory Conditions Policy Group is set up by NCPC, chaired by John Mount, then NCPC trustee and CEO at St Catherine’s Hospice. Group includes the needs of people with heart failure at the end of life within its remit.</td>
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<tr>
<td>Dec 2005</td>
<td><em>Palliative Care in Heart Failure: Moving Forward Together</em> event takes place in Birmingham</td>
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<tr>
<td>Jan 2006</td>
<td>Group publish <em>Focus On Heart Failure – A National Survey of Heart Failure Nurses &amp; Their Involvement with Palliative Care Services</em></td>
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<tr>
<td>Jan 2006</td>
<td>NCPC host <em>Palliative Care and Heart Failure: Moving Forward</em></td>
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<td>Date</td>
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<tr>
<td>June 2007</td>
<td>The Circulatory and Respiratory Conditions Policy Group splits into two groups - Chronic Respiratory Disease (CRD) Group and the Heart Failure &amp; Renal Group. The CRD group continues under John Mount (see separate timeline). The HF Group is chaired by Dr. James Beattie NCPC Trustee and Consultant Cardiologist; NHS Improvement (Heart Failure) Clinical Lead.</td>
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<tr>
<td>July 2007</td>
<td>Discussion document is produced by Jim Beattie for BHF with NCPC input <a href="#">Implantable cardioverter defibrillators (ICDs) in patients who are reaching the end of life</a></td>
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<td>May 2008</td>
<td>Group joins the <a href="#">Cardio and Vascular Coalition</a></td>
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<td>June 2008</td>
<td>Group run workshop at British Cardiovascular Society annual conference entitled <a href="#">Advanced heart failure: optimum clinical care includes embedded supportive strategies</a></td>
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<tr>
<td>March 2009</td>
<td>Cardio and Vascular Coalition's <a href="#">Destination 2020: a plan for cardio and vascular health</a> published including a section on end of life care</td>
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<tr>
<td>June 2009</td>
<td>Publication of <a href="#">End of Life Care in Advanced Kidney Disease</a> by the National End of Life Care Programme, to which the group had contributed</td>
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<tr>
<td>July 2009</td>
<td>Jim Beattie and Emily Sam present on palliative care for heart failure and the group’s work to the Dept of Health Heart Disease Programme Board chaired by Roger Boyle</td>
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<tr>
<td>October 2010</td>
<td>Poster of NCPC’s HFNS survey published at the International Congress on Palliative Care in Montreal</td>
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<tr>
<td>March 2011</td>
<td>The survey is published in full in the European Journal of Cardiovascular Nursing – <a href="#">more information</a></td>
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<tr>
<td>September 2011</td>
<td>Group publishes the results from two national surveys of heart failure nurses carried out in 2005 and 2010 in a NCPC briefing. <a href="#">Strengthening the relationship between heart failure nurses &amp; specialist palliative care: Results from two national surveys – 2005/2010 – more information</a></td>
</tr>
<tr>
<td>March 2012</td>
<td>On 22nd March 2012 the group, with funding from the British Heart Foundation and Marie Currie Cancer Care, hosted our second national heart failure conference which focused on breaking down the barriers to end of life care in heart failure – <a href="#">more information</a>.</td>
</tr>
<tr>
<td>Present</td>
<td>The group are currently exploring the ICD deactivation policies in hospices and other specialist palliative care units, and preparing a <a href="#">Difficult Conversations</a> for heart failure booklet.</td>
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About NCPC

The National Council for Palliative Care (NCPC) is the umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland. We believe that everyone approaching the end of life has the right to the highest quality care and support, wherever they live, and whatever their condition. We work with government, health and social care staff and people with personal experience to improve end of life care for all.

NCPC is a registered charity number 1005671 and a company limited by guarantee number 2644430. Visit www.ncpc.org.uk for more information.

We lead the national Dying Matters coalition, which currently has over 15,000 members, to change knowledge, attitudes and behaviours towards dying, death and bereavement, and through this to make ‘living and dying well’ the norm. Visit www.dyingmatters.org for more information.

References


3 National End of Life Care Intelligence Network & National End of Life Care Programme What do we know now that we didn’t know a year ago? New intelligence on end of life care in England [www.endoflifecare-intelligence.org.uk/resources/publications/what_we_know_now.aspx]


5 Minimum Data Set (MDS) for Specialist Palliative Care Service 2010/11 NCPC (Due to be published shortly) www.ncpc.org.uk/page/MDS

vii National End of Life Care Intelligence Network & National End of Life Care Programme What do we know now that we didn’t know a year ago? New intelligence on end of life care in England [www.endoflifecare-intelligence.org.uk/resources/publications/what_we_know_now.aspx]

viii National End of Life Care Intelligence Network & National End of Life Care Programme What do we know now that we didn’t know a year ago? New intelligence on end of life care in England [www.endoflifecare-intelligence.org.uk/resources/publications/what_we_know_now.aspx]


xii Focus on Heart Failure: A national survey of heart failure nurses and their involvement with palliative care services (NCPC 2006) and Strengthening the relationship between heart failure nurses & specialist palliative care: Results from two national surveys – 2005/2010 (NCPC 2011) www.ncpc.org.uk/page/HFNS-Survey