All Party Parliamentary Group on Heart Disease

Inquiry: Living with Heart Failure

Call for written evidence

Background to the Inquiry

Heart failure is a complex clinical syndrome of symptoms and signs that suggest the heart is not pumping blood around the body as efficiently as it should. It is most commonly caused by damage to the heart muscle, for example as the result of a heart attack, cardiomyopathy or related to high blood pressure. Symptoms include breathlessness, fatigue and fluid retention. Heart failure can be chronic or acute; someone with chronic heart failure may also have episodes of acute heart failure.

Over half a million people in the UK have been diagnosed with heart failure[1] and there are likely to be many more undiagnosed cases. Its prevalence is likely to increase with the combined effect of an ageing population and improved survival from heart attacks. [2,3] Many people with heart failure are older and also have multiple co-morbidities. Despite therapeutic advances, heart failure remains a progressive and currently incurable condition.

We welcome the excellent work that has been undertaken by the National Institute of Health and Care Excellence (NICE) in recent years, at the behest of the Department of Health, to develop evidence-based guidelines for the diagnosis, treatment and management of both acute and chronic heart failure that will improve outcomes for patients.[4]

Some people with heart failure receive excellent treatment and care. There are, however, variations in the treatment and care received by people with heart failure, and many are not receiving care that meets these guidelines. This has consequences for patients, the NHS and beyond.

The survival rate for untreated heart failure is worse than for some cancers.[5] It can be a debilitating and distressing condition that has a major effect on the quality of life of patients, and their families and carers. As well as the physical limitations, heart failure also has an emotional, social and economic impact on those that live with it. Alongside health services, patients may also need to access other help, for example social support.

In addition to the human cost, heart failure is also costly to the **N**HS. It accounts for 2 per cent of the total NHS budget, and one million patient bed days each year. Heart failure is the cause of 5 per

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[1] Quality and Outcomes Framework prevalence data 2014/15, Health and Social Care Information centre, Information Services Division Scotland, Stats Wales, Department of Health, Social Services and Public Safety Northern Ireland.

[2] National Heart Failure Audit 2013/14, National Institute for Cardiovascular Outcomes Research (NICOR) and the British Society for Heart Failure, October 2015. Available here: www.ucl.ac.uk/nicor/audits/heartfailure/reports .

[3] Chronic heart failure in adults: management (Clinical Guideline 108) National Institute for Heath and Care Excellence (NICE), 2010. Available at: www.nice.org.uk/guidance/cg108

[4] NICE has published clinical guidelines, quality standards and pathways for both chronic and acute heart failure. These are available on their website at www.nice.org.uk/guidance/conditions-and-diseases/cardiovascular-conditions/heart-failure .

[5] Stewart S, et al. Population impact of heart failure and the most common forms of cancer. *Circulation: Cardiovascular Quality and Outcomes*, 2010.

cent of all emergency admissions,[6] and is the most common cause of admission in people over 65.[7] The number of admissions for heart failure is likely to rise with an ageing population.[8]

This Inquiry provides a unique opportunity to work collaboratively with patients, healthcare professionals, the Government and NHS England to identify what action can be taken to improve outcomes and experience for people with heart failure, and their families and carers. It will also seek to help the Government and NHS England to deliver on the objectives in the Shared Delivery Plan, Mandate to NHS England and Five Year Forward View, including improving out of hospital care and reducing emergency bed days, and creating the safest, highest quality healthcare services, as well as improving cost effective use of NHS resources.

Call for written evidence

The Inquiry will focus on three key areas of diagnosis; treatment and care; and palliative care. The APPG on Heart Disease is inviting written evidence that addresses the following areas.

Diagnosis

Heart failure is often difficult to diagnose, and it symptoms can be misdiagnosed. We would particularly welcome evidence on the following areas:

- What is the experience of patients of being diagnosed with heart failure? What impact do the difficulties with diagnosing it have on them and their families and carers? What evidence exists around this?

- What evidence exists around the speed and accuracy with which heart failure is diagnosed?

- What are the barriers to timely and accurate diagnosis of heart failure? How can these barriers be overcome?

Treatment and Care

NICE has developed evidence-based guidelines on the treatment and care of people with heart failure. However, there are variations in treatment and care, and many heart failure patients do not receive care that meets these guidelines. Specialist input from a multi-disciplinary heart failure team, including heart failure specialist nurses, improves outcomes for patients, but there are particular issues with patients not receiving specialist input. We would particularly welcome evidence on the following areas:

- What is the experience of patients of the treatment and care they receive for heart failure? What impact does this have on patients, their families and carers? What evidence exists around this?

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[6] All figures from the National Heart Failure Audit 2013/14, NICOR and the British Society for Heart Failure, October 2015. Available here: www.ucl.ac.uk/nicor/audits/heartfailure/reports .

[7] Acute heart failure: diagnosis and management (CG187), NICE, October 2014. Available at: www.nice.org.uk/guidance/CG187 .

[8] Chronic heart failure: Management of chronic heart failure in adults in primary and secondary care (CG 108) NICE, 2010. Available at: www.nice.org.uk/guidance/cg108

- What are the barriers to patients receiving specialist input to their care? How can these barriers be overcome?

- What evidence exists about how well heart failure is managed in the community? For example, how many heart failure patients have their condition reviewed every six months, and have a review within two weeks of any change in medication, as set out in guidelines?

- What evidence exists around how well older people with both heart failure and other co-morbidities are treated and cared for?

- What more can be done to help prevent people with heart failure being admitted to hospital?

Palliative care

Comparatively few people with heart failure receive palliative care. The unpredictable course of heart failure means many are not identified as approaching end of life, and can make clinicians reluctant to discuss this issue with them. We would particularly welcome evidence on the following issues:

- What is the experience of patients with heart failure, and their families and carers, of palliative care? What impact does this have on them? What evidence exists around this?

- What are the barriers to patients with heart failure being identified as approaching the end of life and accessing palliative care? How can these barriers be overcome?

Heart failure can affect people of all ages. We recognise that early diagnosis and the right treatment and care are vitally important at any age. However, as the majority of people with heart failure are older, the Inquiry will focus on heart failure in adults. Although the Inquiry will not cover the process and issues around transplantation, the experience of patients with heart failure post-transplant will be in scope. The Inquiry will cover the three areas highlighted above in relation to England.

Submitting your evidence

Written evidence submitted should be no more than 3,000 words.

All submissions should be sent by email to Catrin Pritchard at pritchardc@bhf.org.uk by 5pm **Friday 8th April 2016** or via post to:

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We may publish the submissions we receive. The written evidence received, alongside the oral evidence, will inform the report of the Inquiry.

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