Evidence Based Scan for My Health My Community (MHMC)

Pennine Care NHS Foundation Trust

HF and Staying Well

&

HF and EoL care

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The National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care (NIHR CLAHRC) Greater Manchester is a partnership between providers and commissioners from the NHS, industry, the third sector and the University of Manchester. We aim to improve the health of people in Greater Manchester and beyond through carrying out research and putting it into practice.
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Executive summary

This EBS is divided into a number of parts, with heart failure (HF) and staying well (Part 2); HF and end-of-life (EoL) care and advanced HF (Part 3) being perhaps the two most pertinent to the My Health My Community (MHMC) project team.

Part two: HF and staying well emphasises that the relationship between prognostic indicators and clinical outcomes is often weak; with each HF patient having their own unique disease trajectory. Each “phase” of the HF trajectory has different needs and these are explored here and throughout this evidence based scan (EBS). Also, in the black, Asian and minority ethnic (BAME) context, health care professionals (HCPs) should be aware of different aetiologies that are prevalent in various home regions (for example, diastolic HF or HF with preserved systolic function is especially common in patients of Chinese, black and Aboriginal descent and certain ethnic groups are particularly susceptible to the development of hypertension and obesity).

An expert information gathering exercise was undertaken with nine HCPs working in the field in terms of how the family caring experience would be for HF, and whether carers can support HF patients in both keeping well and at the end of their life. The general consensus of opinion was that, carers could undertake this with coaching, support from HCPs and with proper resources. Some carers may not be mentally or physically prepared for the unpredictability of HF, or may be too elderly themselves to undertake the task however.

Appropriate engagement in HF self-care by patients and carers has the potential to reduce HF costly readmissions and health care costs, and to improve health-related quality of life. Thus carers are key to successful HF self-care and current guidelines suggest that they be involved in this vital education, particularly about dietary requirements. The health literacy of carers is addressed in terms of the broad set of reading, writing, mathematical and communication skills that support them (and patients) to understand health information, implement basic self-care activities, and navigate health care systems. Low literacy can result in poor health behaviours, inadequate self-management of chronic diseases, increased hospitalisation and higher health care, this group being more likely to have a poorer understanding of their chronic disease generally.

Particular methods of teaching are effective in HF interventions such as Motivational Interviewing (MI). Other conceptual frameworks for supporting carers of HF patients are described along with some successful interventions which have used a combination of these. These include: an intervention for symptom management control and coaching for dyspnoea and physical functioning; family support for self-care; and the efficacy of health education booklets in improving medication adherence. A North West of England Study “COINCIDE” for depression is described in detail because this has involved patients with depression comorbid with cardiovascular disease. This is now being taken up in Improved Access to Psychological Therapies (IAPT) services as part of a phased National Institute for Health Research (NIHR) CLAHRC

Greater Manchester funded roll out and evaluation of collaborative care for people with long term conditions and common mental health problems.

In addition to guidelines for developing printed educational materials, there is a substantial, tabulated section on curriculum, ideas for carer education and support for staying well with HF. This is offered in terms of numerous carer tasks and issues related to keeping both patients and carers well during HF. Strategies, and guidelines pertaining to these are outlined with educational programmes and the numerous paper, web based and film resources available along with findings from on-going and completed studies which address and meet these needs. Needs and issues include differential diagnosis, knowledge of the HF trajectory, understanding medical terminology, carer assessment/support/health, carers' need to be vigilant and monitor patients for change, emergency admissions/discharge home and communication issues with HCPs. Lifestyle issues are addressed and include: diet, weight management and alcohol consumption. Clinical issues to address include: pain, anxiety, cognitive impairment, iron deficiency and breathlessness. A major message is that patient and carer education and support is absolutely key to HF management.

Part three: examines EoL care and advanced HF. End stage HF is usually associated with a risk of sudden death being dramatically increased and for a considerable proportion of patients dying of cardiovascular disease their death is perceived as sudden and/or unexpected by relatives. The unmet needs of HF patients in relation to palliative care (only around 6% of those dying with HF being referred to palliative care) are considerable. Barriers to referral include difficult prognostication due to the unpredictable disease trajectory and inadequate initiation of conversations about EoL care. Responding to the individual needs of these patients, and the needs of their carer is an enormous challenge for both health and social care and novel approaches to EoL planning are required in advanced HF. HF care involves complex technical issues and drug regimes, and there is a clear role for specialist palliative care in the terminal phase of HF. Thus palliative care could contribute to HF EoL care especially in the terminal phases. The evidence suggests, however, that EoL care in HF is poor. It is important to explore how PC programmes should be integrated into the care of HF patients and also meet carer's needs.

Main issues in EoL care including deactivation of defibrillator issues and breathlessness are documented and addressed with excellent HF EoL specific programmes and resources being described. BAME and Lesbian, Gay, bisexual and Transgender (LGBT) carer needs are acknowledged and addressed. Some examples of HF good practice are included. Clinical guidelines are documented.

Many up to date resources have been presented to the My Health, My Community (MHMC) project team with this EBS.

Section 1. Introduction

This EBS will focus on cardiovascular disease (CVD); specifically heart failure (HF), offering evidence based recommendations for staying well and the EoL from the perspective of carers.

Given that when living in a marriage-like relationship it is usually one partner who cares for the other (Agren, Evangelista et al. 2010), the term "carer" in this EBS encompasses, "partners" "spouse", "significant other", and/or person living in an intimate relationship including, Black, Asian, Minority Ethnic (BAME) and Lesbian, Gay, bisexual and Transgender (LGBT) with a "patient" (an individual with HF).

1.1 Background: Definition and Epidemiology of CVD

Historically, CVD has been the biggest single and most common cause of death in England. In 2011, the proportion of all deaths attributable to circulatory diseases fell below that of cancer for the first time; although stroke remains a significant cause of disability[1]. In terms of regional differences, there are higher directly standardised mortality rates in the North of England (including the North West) (NHS 2013). Globally, an estimated 17 million people die of CVD every year, particularly from heart attacks and strokes. This occurs equally in both sexes. Given the increasing ageing population, CVD is estimated to become the leading cause of death in developing countries, with over 80% of CVD deaths occurring in low and middle-income countries.

http://www.euro.who.int/en/health-topics/noncommunicable-diseases/cardiovascular-diseases/cardiovascular-diseases2

CVDs are a complex group of disorders and associated comorbidities which may be difficult to fit into the ICD-10[2] codes structure alone (NHS 2013) because they can include all of the following:

All circulatory diseases:

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[1] *Please see Stroke and End of Life Care EBS*

[2] *The single "underlying" cause of death for each patient is determined from the death certificate by the ONS and coded using the ICD-10 system NHS (2013). Deaths from cardiovascular diseases. Implications for end of life care in England. NHS National End of Life Care Programme. Improving end of life care. National end of life care intelligence network.*

- Abdominal aortic aneurysm
- Cardiac arrhythmias
- Cerebrovascular disease - disease of the blood vessels supplying the brain. The largest proportion of deaths from acute cerebrovascular diseases occurs in those aged 80+
- Chronic coronary heart disease - disease of the blood vessels supplying the heart muscle
- Other circulatory diseases e.g., Peripheral arterial disease (disease of blood vessels supplying the arms and legs)

All cardiovascular diseases. All of above plus:

- Transient ischaemic attacks
- Congenital heart disease - malformations of heart structure existing at birth). The largest proportion of deaths from congenital heart disease occurs in those aged between 0–39 with an inverse association with age
- Vascular dementia (not included in this EBS)
- Rheumatic heart disease[3] - damage to the heart muscle and heart valves from rheumatic fever, caused by streptococcal bacteria)(NHS 2013)

Between 2004 and 2011, the number of deaths from abdominal aortic aneurysms, acute cerebrovascular disease, acute coronary heart disease, chronic coronary heart disease (more men than women dying of both acute and chronic coronary heart disease) and congenital heart disease have all decreased in line with the overall trend for cardiovascular diseases as a whole. The number of deaths from cardiac arrhythmias increased over the same period however. The National EoL Intelligence Network reports that, notwithstanding that deaths from CVD as a proportion of all deaths have decreased in recent years, CVD remains a leading cause of death in England (NHS 2013).

Whilst the proportion of deaths in usual place of residence (DUPR) for cardiovascular diseases has increased from 37.4% in 2004 to 42.6% in 2011, 59% of cardiovascular disease deaths still occur in hospital thus more work is required to ensure that CVD patients are supported to die with dignity in their preferred place of death. As mentioned above, there are comorbidities associated with CVD which may be difficult to fit into the ICD-10 classification. Such patients may need specific clinical input and funding for more complex EoL Care needs. EoL Care, therefore, requires a holistic, patient-centred, multidisciplinary approach and the care of CVD patients is of significant concern (NHS 2013)

HF (HF) Epidemiology and prevalence

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[3] *Rheumatic heart disease, Chagas and coronary artery disease (CAD) should be considered in those who recently arrived from South America. Rheumatic heart disease should also be considered in patients who recently immigrated from Africa. Howlett, J. G., et al. (2010). "The 2010 Canadian Cardiovascular Society guidelines for the diagnosis and management of heart failure update: Heart failure in ethnic minority populations, heart failure and pregnancy, disease management, and quality improvement/assurance programs."* Canadian Journal of Cardiology ***26****(4): 185-202.*

Over 23 million people worldwide suffer from HF (HF). Already at epidemic proportions, this significant global public health problem is predicted to escalate exponentially over the next decade. In the US currently, over five million people have HF and by 2030 it is expected that eight million people will be diagnosed with HF (Srisuk, Cameron et al. 2014). HF is being mentioned on one in eight US death certificates (Barclay, Momen et al. 2011, Doherty, Fitzsimons et al. 2015).

HF is a complex clinical syndrome of symptoms and signs in which structural or functional abnormalities result in, or increases the subsequent risk of, clinical symptoms and signs of low cardiac output or pulmonary or systemic congestion (Gruszczynski, Schuster et al. 2010). Progressive pump failure is the more common mode of death in advanced disease and impacts considerably upon the psychological and physical health of family caregivers (Barclay, Momen et al. 2011). Most of the evidence on treatment is for HF due to left ventricular systolic dysfunction (LVSD). The most common cause of HF in the UK is coronary artery disease and many patients have had a myocardial infarction in the past. HF is predominantly a disease of older people with all their attendant comorbidities. At least 5% of those aged over 75 years are affected, rising to about 15% in the very old. The prevalence of HF is expected to rise in future as a result of an ageing population, improved survival of people with ischaemic heart disease and more effective treatments for HF (Connolly, Beattie et al. 2014).

HF is unpredictable, progressive, and incurable (Rocker and Cook 2013). Around 1 million UK citizens live with HF (Jorge Alves, Ribeiro et al. 2010) with 6.5 million people living with HF in Europe, with approximately 60,000 new cases being reported every year (Connolly, Beattie et al. 2014). People with HF have a poor prognosis: 30–40% of patients diagnosed with HF dying within a year (Jorge Alves, Ribeiro et al. 2010) (Barclay, Momen et al. 2011), mortality then falling to less than 10% per year (Jorge Alves, Ribeiro et al. 2010) with 60% dying within 5 years (Barclay, Momen et al. 2011). Despite recent advances in the management of Chronic HF (CHF), the prognosis of many of these patients remains extremely poor (Jorge Alves, Ribeiro et al. 2010) worse than for many cancers (Barclay, Momen et al. 2011).

HF is a high cost Healthcare Resource Group (HRG) and multiple hospital admissions - with disabling symptoms of a similar prevalence to those of patients with advanced cancer (Barclay, Momen et al. 2011) (Srisuk, Cameron et al. 2014) common in advanced HF, account for a significant public health care resource and expenditure. For the year 2007- 2008, there were almost 60,000 admissions with HF in England and Wales, requiring more than 750,000 bed days. Some of these admissions might be avoided with anticipatory care planning and the provision of community health and social care support (Connolly, Beattie et al. 2014).

1.2 The HF trajectory

HF is a chronic long term condition that can develop at any age becoming more prevalent with increasing age. It is estimated that between 1-2% of the population under 65 years of age have HF, increasing to 7% for people between the ages of 75-84 years, and to a further 15% in people older than 85. It is the most common cause of hospitalisation in patients over 65 years of age and is associated with high health expenditure. Healthcare related costs for patients with HF have been estimated to amount to 2% of the total budget of the UK NHS. HF is associated with reduced physical and mental health, quality of life decreases and, although some patients survive for many years, the condition usually worsens over time and patients require constant care (Ove Arup & Partners Ltd 2010).

The relationship between prognostic indicators and clinical outcomes is often weak (Jorge Alves, Ribeiro et al. 2010). Thus the course of HF is extremely unpredictable, each patient having their own unique disease trajectory which cannot be reliably anticipated (Connolly, Beattie et al. 2014). Prediction of the time of death of patients is almost impossible and confounds the best of prognostic models. To illustrate, around 50% of deaths in HF are sudden, especially in the less severe stages, from arrhythmias or ischaemic events. Many of these patients are reported to have had a good quality of life in the month before they died. More than half of those with HF dying within 3 days had been estimated to have a prognosis of over 6 months (Barclay, Momen et al. 2011).

There are five typical phases identified within the trajectory of HF and these are described below in Table 1.

The course of HF and the time spent progressing through these illness phases varies considerably between individuals. Clinical deterioration and death may occur at any time within these phases. Connolly identifies a number of clinical features which often become evident and which imply that the situation is irrecoverable and when formal EoL care is required. These are described below on page 16, figure 1.

Despite therapeutic advances, HF remains a progressive, incurable and ultimately fatal long term condition (Connolly, Beattie et al. 2014). The symptomatic burden and mortality risks in HF are similar to common cancers and of all general medical conditions HF has the greatest impact on quality of life, patients often having multiple, complex needs. HF patients experience fatigue, breathlessness, limited mobility, a restricted social life, poor quality of life and have complex medication regimens. All factors have a major impact on the psychological and physical health of both patients and their family caregivers (Barclay, Momen et al. 2011) (Connolly, Beattie et al. 2014). Cognitive impairment is common in HF and impacts upon many aspects of the condition. Although HF patients spend most of their last year of life at home, 59% of them die in hospital (Connolly, Beattie et al. 2014).

Low socio-economic status, lack of social support, stress at work and in family life, depression, anxiety, hostility, and the type D personality contribute to the worsening of clinical course and prognosis of CVD. These factors act as barriers to treatment adherence and efforts to improve lifestyle, as well as to promoting health and well-being in patients and populations. In addition, distinct psycho-biological mechanisms have been identified, which are directly involved in the pathogenesis of CVD (Perk J, De Backer G et al. 2012).

In the literature, phases of HF are usually based on the New York Heart Association Classification (Kubo, et al, 2004). These comprise:

- Class I: No limitation of physical activity. Ordinary physical activity does not cause undue breathlessness, fatigue, or palpitations.
- Class II: Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in undue breathlessness, fatigue, or palpitations.
- Class III: Marked limitation of physical activity. Comfortable at rest, but less than ordinary physical activity results in undue breathlessness, fatigue, or palpitations.
- Class IV: Unable to carry on any physical activity without discomfort. Symptoms at rest can be present. If any physical activity is undertaken, discomfort is increased.

A diagram depicting an alternative view of the HF Trajectory is below, each phase being further described below in

Figure **1** which briefly outlines carers' needs relating to each phase.

Figure 1 EoL Care in HF (Connolly, Beattie et al. 2014)

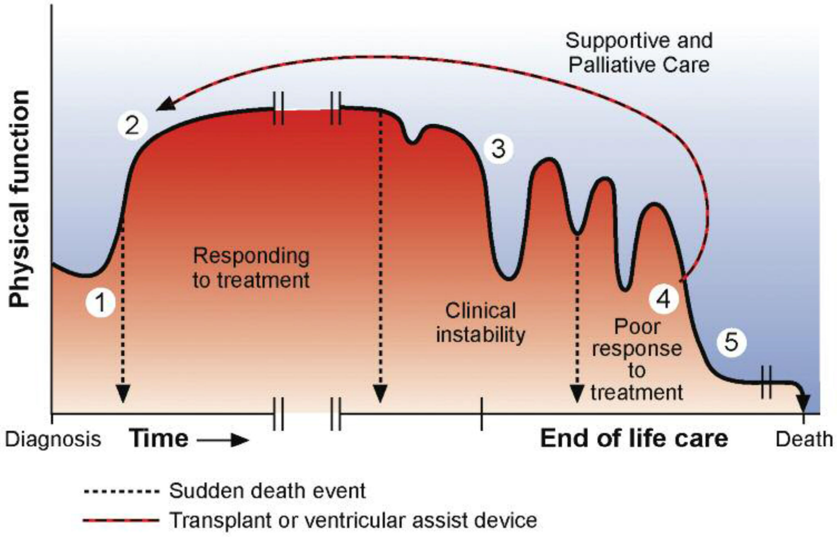

Table 1 Description of EoL Care phases in HF and their related needs

Phases	Description of the phase[4]	Needs
1	Symptom onset, diagnosis and initiation of medical treatment. This often occurs as the patient is admitted to hospital with a life-threatening episode of breathlessness. Some patients may die at this point. However, for other patients the onset of symptoms is more gradual, and they may present to the general practitioner (GP) with slowly progressive fluid retention and/or breathlessness. With either presentation, once the diagnosis is confirmed, treating the patient with drug therapy, combined with cardiac surgery if required, will often produce a dramatic improvement in symptoms. Patients usually now enter a plateau period of variable duration, sometimes lasting several years.	Patients and carers need education on: • the nature of HF • the treatment options • advice on diet and fluid management Advice on advance care planning including: • An advance statement - not legally binding but must be taken into account by those making proxy decisions in the patient's best interest • Advance decision to refuse treatment (ADRT). Legally binding. • Lasting power of attorney (LPA). Legally binding if properly formulated and recorded when the patient has capacity and requiring registration with the Office of the Public Guardian. All forms of advance care planning may inform decisions by clinicians on the policy for cardiopulmonary resuscitation
2	During this period patients generally remain under the care of their GP. They should be advised how to monitor their condition at home and when to call for help because life expectancy is so difficult to predict and patients feel relatively well, most HCPS are reluctant to talk to patients or carers about their prognosis at this point	Ongoing support and education for patients and their carers at this point can promote: • autonomy • self-care • adherence to therapy • a reduction in the risk of inappropriate admission
3	Patients develop periods of instability with recurrence of symptoms linked to deterioration in heart function. Rebalancing of treatment may restore stability, but often a new approach is required with the use of implantable	Increased patient and carer support is required with a major role for Community HF nurses. Regular review including home visits may help to avoid unnecessary

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[4] *Abridged from End of life care in HF. A framework for implementation. Connolly, M., et al. (2014). "End of life care in HF. A framework for implementation."*

	cardiac devices to improve heart pump performance (cardiac resynchronisation therapy) or to shock the heart back to normal rhythm (implantable cardioverter defibrillator (ICD) in the event of a life-threatening arrhythmia.	hospital admissions.
4	Patient experiences increasing symptoms and exhibits declining physical capacity, despite optimal therapy. Consideration for other treatment options such as cardiac transplantation may be considered in this phase. Judging the right time to discuss prognosis and advance care planning with a patient can be very difficult.	The reappearance of symptoms described in phases 3 and 4 and raising the question of the possible need for aggressive intervention often presents an opportunity to initiate discussion on EoL Care.
5	Care goals need to be openly reviewed with the treatment emphasis shifting to managing symptoms rather than the futile continuation of therapy offered only for prognostic benefit. Formal assessment of supportive and palliative care needs is required at this time and specialist palliative care may need to be involved. Multi-organ failure is the usual terminal mechanism in this phase, whereas sudden arrhythmic cardiac death is more common in earlier phases. Review of resuscitation status and reprogramming of cardiac devices may be important management issues. Deactivation of ICDs is frequently left almost to the point of death when agonal arrhythmias may trigger device discharges, disturbing the patient and distressing the family.	In this terminal phase, the situation often progresses rapidly. Unless treatment policies have been defined in advance, care at this stage has the potential to become disorganised.

PART 1

Section 2. Methods

2.1 Expert Information Gathering Exercise (EIGE)

An expert information gathering exercise (EIGE) was undertaken for the EBS because it offers views from those in the field and adds to meaning and context. The author of this review contacted 9 HCPs and others working in the field with the following questions:

1. Can family carers help people with CVD keep well?
2. Are there some conditions in the area of CVD for which there is a role for family carers to care for people at the EoL in their own home?
3. How prepared do you think they are for this role?
4. Could they receive training and support in order to keep well/to undertake the various tasks involved in caring in this context

An initial email to each individual was sent out on 15 August 2015, and again on 14 September 2015. The individuals contacted are identified as follows:

1. CLAHRC Facilitator working on GM-HFIT
2. Professor and Nurse Specialist in Cardiology
3. Academic & Consultant (cardiology)
4. Professor of Nursing
5. 3 x HF Specialist Nurses (HFSNs) working on GM-HFIT
6. Professor of Nursing & Applied Health Research
7. NIHR Clinical Lecturer in Palliative Medicine

The responses to these key questions are described in table 2 below

Table 2 Responses from the expert scoping work

Respondent	Question 1	Question 2	Question 3	Question 4
3	Certainly, and they play a big role. They help to monitor symptoms (and sometimes insist that patients seek help when the patient may be reluctant to do so), help with therapy and self-management like walking/exercising with the patient, reminding to take medications, keeping to a healthy diet (or may be the one that prepares the meals); they may be the ones that interpret or communicate what a health care provider says (or communicate with the HCP about the patient), serve as transport, and of course the emotional support that they provide.	Absolutely! Family carers are remarkable in what they often take on (people do go home with ventricular assist devices and even total artificial hearts), and for most conditions there is no reason why carers could not provide care at home at EoL as long as they are properly supported and that there are resources available. One caveat: CVD like HF is predominantly a disease of the elderly, and so spouses are often also elderly with comorbidities of their own. We have to be sure that both patient and carer prefer this.	That really depends on the carer and the providers (e.g. what information, education, support has been provided and understood). Some carers will be very well prepared, some not much.	I see no reason why not; again if they are willing, interested and mentally/physically able to do it. Training and support should be able to be tailored to the carer and the situation, and accessible support available if things go wrong or the carer becomes overwhelmed. People can find this a very satisfying experience.
4		Yes, particularly for HF which is the end phenotype of most CV diseases and has a poor prognosis with mortality rates similar to many cancers. I don’t think EoL Care is optimised for this group of patients as it is for cancer services	Not very from the patients that I see in clinic. I don’t think that many HF patients appreciate that the prognosis is poor and not many of them have EoL conversations. There is a role for palliative care involvement in HF	I guess it would depend on what the training and support would be and what you would expect them to do? Certainly support would be important. Maybe extend role of Macmillan nurses or community palliative care team to see these patients, have formal referral pathways etc.

5 (3 HFSNs)	Yes, evidence from EuroAction[5] supports family involvement in lifestyle change as a means to promote adherence.	Yes end stage HF is a good example. Carers are really important but they are often the spouse, of a similar age and with similar health problems to the HF patient, but often these carers don't receive much help and support patients to the detriment of their own health.	To my knowledge there is little or no preparation available.	Yes that could be very important but is as yet untested.
6	Family/carers can help patients to keep well if they are appropriately coached (perhaps a better choice of word than educated?) on the signs and symptoms of decompensation to look out for. Often I find that earlier input from specialists could have alleviated symptoms sooner, avoided hospital admissions hopefully.	With regard to HF, patients are highly symptomatic in the end stages where they are suffering from progressive decline. I would think there is a role for them with regard to the anxiety that escalates in patients when symptoms increase. Nothing will replace the required specialist input, but there will always be limits on resources and time that can be spent with patients, which is where carers/family can support.	I don't think many are well prepared. It is something I talk about with patients and family but as the condition is so unpredictable it is difficult to plan for such. These patients are always at increased risk of life threatening arrhythmia so there is always unpredictability.	I would think coaching in monitoring for decompensation and mood changes is important - looking for trigger points to escalate intervention. Perhaps counselling courses on dealing with long term illness and End of Life. As regards keeping well the carer/family must acknowledge their limitations or their role as part of the care pathway. To overstep would likely only serve to increase stresses.
7	Yes they can support self-management but also hinder it so it depends on the type of support	Yes, I believe this would apply to any health condition as I would think most people would prefer to die at home	Not prepared as the HF trajectory is unpredictable and discussion about EoL are problematic as death remains a taboo subject for most	Yes, there are studies in Stroke care in which this has been done. However it needs to be understood that not all carers want to care!

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[5] http://www.escardio.org/The-ESC/Initiatives/EuroAction *Nurse-coordinated multidisciplinary, family-based cardiovascular disease prevention programme (EUROACTION) for patients with coronary heart disease and asymptomatic individuals at high risk of cardiovascular disease: a paired, cluster-randomised controlled trial (Wood et al, 2008).*

2.2 Academic search criterion

As in the supplemtory Evidence Based Scan (EBS) as part of this series of work for the My Health My Community (MHMC) project team; this EBS is pragmatic and uses some of the principles of 'evidence scans' as described by the Health Foundation (The Health Foundation 2010). This approach provides information to help those involved in improving the quality of healthcare to understand what research is available on particular topics. The purpose is to provide a synopsis of evidence to help inform discussions and to help identify if there is need for further research or development in the area covered. It can also provide a rapid collation of empirical research about a topic. Although all of the evidence is sourced and compiled systematically, this is not classed as a systematic review. That is, it does not seek to summarise theoretical literature or to explore in any depth the concepts covered by the scan or those arising from it. Elements of 'berry picking' were also used. This is another structured method of searching which also allows for an iterative and creative searching process to take place (Barroso and Gollop 2003) such as citation searching, reference and author chasing. The whole process involved:

- Meetings and communications with stakeholders
- A Google grey literature search for any education programmes/initiatives. (This included health provider sites and websites with a target audience of patients/carers coping with terminal illness, advanced illness and EoL issues.)
- An examination of related websites, reports, conference presentations and academic papers
- Personal communications with programme leads and/or researchers
- A University of Manchester library academic search
- An appraisal of existing programmes and initiatives
- Recommendations for practice

Table 3 summarises the academic search criteria. The search included papers from 2010-2015 in the English language. The time period of five years was decided upon because of the complexity of HF and its trajectory and various prognoses and the time constraints for the completion of the EBS. English language articles were selected. Newspaper articles, books or primarily clinically focused papers were excluded. Additional papers were identified from previous phases and following another search before finalising this document.

Table 3 Academic search

Sources	Terms
University of Manchester search[6] Google Scholar Search Google search • Journal Searches • British Journal of Cardiology • Author searches • Subject searches, e.g. Breathlessness, defibrillator issues • Resource searches via ○ E-mail ○ Personal communications ○ Google ○ Citation/reference/author chasing	HF and… *'Management'* *'End of life'* *'Palliative care'* *'Terminal care'* *'Family carers'* *'Lay-carers'* *'Home care'* *'Burden'* *'Needs'* *'Death'* *'Dying'* *'Bereavement'* *'Pain management'* *'Educating carers'* *'Cognitive decline'*

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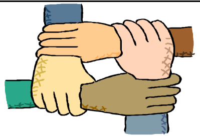
[6] *This search covered; Taylor & Francis Online – Journals, SpringerLink Open Access SpringerLink SciVerse ScienceDirect (Elsevier) SAGE Journals Public Information Online (Dandy Booksellers) PMC (PuBAMEd Central) Oxford Journals (Oxford University Press) MEDLINE/PuBAMEd (NLM) Literature Resource Center (Gale) C.E.E.O.L Journals Karger Journals IngentaConnect Emerald Journals (Emerald Group Publishing) Duke University Press Journals Online Directory of Open Access Journals (DOAJ) Cambridge Journals (Cambridge University Press) BioMed Central ACM Digital Library ERIC*

2.3 Flag system for appraising evidence

As in the other EBSs in this series the flag system below offers the MHMC project team an appraisal of the evidence provided herein.

☼	**VERY RELEVANT TO PCFT** Worth contacting this initiative
✡ ✡	**DENOTES VERY GOOD PRACTICE** This could mean that the programme/guideline/initiative: • Is established practice • Has been nominated for an award • Has won an award • Is a completed successful pilot • Is part of a larger programme • Is the subject of a peer reviewed paper • Meets a number of important guidelines
✡	**DENOTES GOOD PRACTICE** This could mean that the programme/guideline/initiative could have been funded
📜	**ENDORSED, RECOMMENDED BY…**
?	**PILOT STUDY**

	**A CO-DESIGNED INITIATIVE** with lay and professionals
	**COMPLETED INITIATIVE**
	**ONGOING INITIATIVE**
	**HAS A BAME/LGBT COMPONENT**

In addition, recommendations in red boxes are also red flag recommendations for PCFT.

PART 2: STAYING WELL WITH HF

3.1 Introduction

Although they currently constitute the largest condition-specific group of non-cancer patients, HF patients themselves are relatively understudied and little is known about the HF caregiver experience and what constitutes the best care and support for them (Mellon, Pring et al. 2013). HF being a complex cardiac syndrome, carers have to deal with clinically unstable patients with responsibility for managing and titrating their medication according to symptoms and frequent admissions to acute care. There are both negative (demands on caregivers' physical and psychosocial well-being) and positive (carers describe feelings of shared responsibility of caring with professional carers and the reward of supporting a loved one, which creates a new role in their relationship) (Whittingham, Barnes et al. 2013).

Caregiving responsibilities have increased as hospital length of stay became shorter. At discharge, the responsibilities for self-care management are put on the patient and partner. A main reason for partners long term support is predominantly emotional bonds. High marital quality has been found to significantly improve 8-year survival in patients with chronic HF and awareness of the needs and contributions of patients' families is increasingly acknowledged. They have an important part to play in enhancing patient adherence to complex medical treatment, encouraging self-care behaviour and influencing the wellbeing of the patient. Living alone with HF increases the risk of psychological stress and is more often associated with poor adherence and self-care and recurrent hospitalisations (Agren, Evangelista et al. 2010).

Caregiving can be associated with increased self-esteem, pride, gratification and a closer relationship with the patient (Whittingham, Barnes et al. 2013) (Agren, Evangelista et al. 2010) (Imes, Dougherty et al. 2011). On the other hand, there is the potential for harmful caregiver behaviour in an intimate relationship. Although home care during deterioration of HF can offer patients security, freedom and an increased awareness of their symptoms, this can also result in high levels of deteriorating mental health and quality of life among partners of patients with HF (Agren, Evangelista et al. 2010) (Imes, Dougherty et al. 2011). Agren's 2010 descriptive study found negative caregiver outcomes including greater patient needs for care, cognitive impairment, more physical symptoms, and a risk for clinical depression in the caregiver themselves and nearly a third of partners of patients with HF experienced a medium level of caregiver burden (Agren, Evangelista et al. 2010).

The HF trajectory is cyclical, uncertain and ultimately downward comprising of periods of exacerbation alongside periods of stability. Carer needs vary depending on their HF patients' unique trajectories. Chronic financial worries are a major issue for HF patients and carers both during routine and hospital based treatment (Rocker and Cook 2013). In contrast to cancer patients, applications for state financial assistance and access to palliative care services show a very marked prevalence for cancer patients (Önac, Fraser et al. 2010).

Thus any ‘self’ care for HF often requires the involvement of a key person, often a significant other, who enables the patient to manage the medical regimen at home and maintain a good quality of life (QOL) (Imes, Dougherty et al. 2011). Care provided and performed by partners of HF patients is above and beyond normal spousal assistance (Davidson, Abernethy et al. 2013). Identifying the kind and amount of care activities that partners of HF patients perform will help give them the support and/or education to undertake these. Partners of HF patients are significantly more likely to support their partners both physically and emotionally, including intervening in order to reduce anxiety and depression - a difficult task for anyone (Hwang, Luttik et al. 2010).

Given the complexity of managing HF, a growing number of family caregivers are expected to be involved in managing HF at home in the future. This burden of care is carried out alongside managing normal household responsibilities and carers’ dealing with their own health issues and personal lives. In addition, carers report difficulties with communication between themselves and healthcare providers, especially in times of crisis. This could be problematic because for carers of those with advanced or severe HF, information and guidance from healthcare providers are of the utmost importance at this time. In addition, role strain hopelessness, helplessness, powerlessness, and emotional reactions to caring alongside financial difficulties all challenge carers’ (Imes, Dougherty et al. 2011).

The constant physical and emotional challenges when balancing care for a HF patient include all of the following:

- The disruption of joint and everyday activities with the patient
- Personal activities are curtailed and social isolation ensues
- Uncertainty about the future
- Differences in the quality of relationships
- Disrupted sleep
- Constant vigilance in monitoring a patient’s condition (Imes, Dougherty et al. 2011).

Carers in the HF context are particularly vulnerable if they are:

- young
- female
- have existing physical and emotional health issues

Increased carer burden can occur if:

- the New York Heart Association Score status of the patient is high
- the patient has had recurrent emergency admissions
- the patient has recently been discharged home

- there is low social support available to the carer
- The impact of caring is effected by:
- Perceived carer control
- Types and impact of caregiving tasks
- Demographic factors (Whittingham, Barnes et al. 2013)

Caregiver burden is common in caregivers of patients with HF. High burden was associated with the caregiver’s report of need for greater help with daily tasks and desire for greater communication with the patient, but not with objective measures of the patient’s need for assistance, such as symptoms or functional status, suggesting that burden may be a measure of the caregiver’s ability to adapt to the caregiving role (Garlo et al, 2010).

3.2 Specific challenges for carers

3.2.1 Self-care and carers contributions

There is growing evidence of the potential effectiveness of self-management interventions for HF patients. These underline the importance of patient education about the disease, daily weight, blood pressure monitoring and self-medication (Ditewig, Blok et al. 2010).

Self-management can be defined as: “the individual’s ability to manage symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition, to effect the cognitive behavioural and emotional responses necessary to maintain a satisfactory quality of life, so a dynamic and continuous process of self-regulation is established[7] (Ditewig, Blok et al. 2010).

A systematic review of studies showed that self-management interventions are part of multifaceted HF-programmes but it is difficult to specify and asses which elements of intervention are beneficial because only the effect of the whole programme on outcome measures is assessed (Ditewig, Blok et al. 2010, Boyde and Peters 2014). However, patient education is a main component and this is important so that patients gain awareness of signs and symptoms, to accomplish lifestyle changes and treatment adherence (Ditewig, Blok et al. 2010, Stromberg 2013). However, providing information does not necessarily guarantee they gain knowledge and, increased knowledge does not necessarily increase self-management behaviour (Ditewig, Blok et al. 2010).

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[7] *Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: a review (2002). Patient Educ Couns **48**:177–87.*

There is a situation-specific theory of HF self-care which provides a framework for understanding and evaluating the competencies of HF patients. Self-care refers to a naturalistic decision-making process involving the behaviours patients choose to adopt in order to maintain physiological stability. Appropriate engagement in HF self-care has the potential to reduce HF costly readmissions and health care costs, and to improve health-related quality of life. The evidence shows that patients with HF demonstrate difficulties in complying with recommended self-care regimens and implementing multidisciplinary chronic disease models of care has been found to support this (Srisuk, Cameron et al. 2014), HF being a chronic illness requiring complex treatment regimen over a long period (Radhakrishnan and Jacelon 2012). A key component of these programmes is educating patients to self-care and studies undertaken in Europe, Australia and North America using these have demonstrated that many HF readmissions are preventable. In countries where these programmes have not been utilised, high numbers of HF readmissions are apparent (Srisuk, Cameron et al. 2014).

Patient knowledge, along with social support from informal carers is key to successful HF self-care. Carers' support in helping HF patients perform self-care results in the social well-being of HF patients, HF patients' health outcomes (health-related quality of life, re-hospitalisation, adherence to HF treatment, and optimal engagement in self-care) are all strongly associated with the existence of carers. International guidelines now specify that carers be included in the educational processes that promote HF self-care (Srisuk, Cameron et al. 2014).

When patient self-care begins to fail (indicated by emergent hospitalisations or caregiver reports of difficulty managing HF at home) this can be an indicator for referral to palliative care and a palliative care skill building intervention. However, with added supportive care, patients may be more safely maintained at home for a longer time period. Understanding individual HF patient/caregiver dyad needs will increase the likelihood that that they will be successful in self-care and less likely to need hospitalisation to maintain homeostasis (Buck, Zambroski et al. 2013).

Caregiving can be long term and little is known about informal community caregiving in HF in the period leading to death. In Australia, the average time from referral to a palliative care service to death is 102 days, with 28.5% of people accessing specialist palliative care for longer than six months nationally and these timescales look to be similar across the world as the proportion of people with non-malignant conditions accessing specialist palliative care services is increasing. In addition assistance with the physical aspects of caring for HF patients is an area not been fully addressed (Davidson, Abernethy et al. 2013).

3.2.2 Health literacy

A common aim of self-management interventions is to increase the active participation of patients in managing their own conditions through improving understanding of their disease. However, many patients have difficulty understanding the information delivered by health professionals because of low health literacy, and how and when information is given to them. Research suggests that 40-80% of the medical information patients receive is forgotten immediately; and nearly half of the information retained is incorrect (Thi Thuy, Robyn et al. 2013).

Health literacy refers to a broad set of skills that help patients understand health information, implement basic self-care activities, and navigate health care systems. These skills include reading, writing, and mathematics, as well as the ability to understand spoken communication and to make appropriate care decisions. Navigating the health care system and understanding health information often requires advanced health literacy skills. 43 % of the U.S. adult population has limited literacy. In relation to any medical condition, the level of a person's health literacy can impact on understanding medication directions and warning labels. Low literacy can result in poor health behaviors, inadequate self-management of chronic diseases, increased hospitalisation, and higher health care costs (DeWalt and McNeill 2013) because this group is more likely to have a poorer understanding of their chronic disease (Thi Thuy, Robyn et al. 2013).

Carers believed that difficulties in communication between the family and the health provider, prevented the provider from fully understanding their struggles and challenges in attempting to care for the patient at home. This may be because HCPs are uncomfortable discussing the course and progression of HF and resistant to proffering this information, or because the patients receiving and processing the information did not fully understand it. They may need help with health literacy or literacy issues in general (Imes, Dougherty et al. 2011). Clinician-related barriers may include poor communication with patients, lack of time for consultation, and failure in providing information at a suitable level for patient understanding (Agren, Evangelista et al. 2010).

Patient education is more effective when strategies are tailored to level of health literacy and patient preferences for learning. Written education materials specifically designed for patients with inadequate health literacy, when coupled with appropriate teaching and follow-up strategies, demonstrate beneficial effects on patient outcomes. Interventions specifically designed for HF patients with low literacy implemented in initial one-to-one education sessions which include picture based materials and management plans can also work. Literacy-sensitive manuals and multi-session interventions can be more effective than single sessions for individuals with low literacy. Improvements in HF symptoms can be achieved when education materials are written with specific attention to the instructional design to ensure relevance for people with inadequate health literacy. A consensus statement from the HF Society of America on health literacy for patients with HF identified that clinicians should focus on; recognising the consequences of low health literacy; identifying and then screening patients at risk; documenting literacy levels and learning preferences; and integrate effective strategies to enhance patient understanding (Boyde and Peters 2014).

Patient (and carer) education on lifestyle issues along with communication between other HCPs is key to patients adhering to medical treatments (Gruszczynski, Schuster et al. 2010).

3.2.3 Diet

The foundation for all HF therapy includes non-pharmacological management. Patients' and carers' understanding of the condition can affect how they behave vis a vis lifestyle changes. Diet and lifestyle issues can cause HF exacerbations. Taking precautions with lifestyle can facilitate optimal management in HF and support medication management. It is essential that patients and carers are in possession of information about HF itself and understand how and why factors including exercise, weight,t and fluid intake, interacts with HF. Patient (and carer) education is required in order to effectively manage HF and intensive courses on managing the condition may be appropriate. This, combined with communication between family doctors, cardiologists, pharmacists, and dieticians could result in good adherence to medical treatment targets and could lessen the burden for patients, caregivers and the NHS (Gruszczynski, Schuster et al. 2010).

The issue of health literacy pertains here too. Terminology and measures used by HCPs are not necessarily understood by patients and carers. It can never be assumed that the terms below are understood in the context of HF care. They should all be explained to families, particularly in the BAME context. That is:

- 'restrict' (salt intake)
- saturated fatty acids
- polyunsaturated fatty acids
- trans-unsaturated fatty acids
- processed food
- natural origin
- wholegrain
- fibre

In addition, metric measurements can also be explained or converted to imperial and/or cups, spoon sizes, and sizes of alcoholic measures similarly. Advice about avoiding canned foods and facilitating skills such as reading food labels are also important (Shahriari, et al, 2013) because, these patients and carers are, in the main, elderly and will be more familiar with imperial and older methods of measurement. In addition they may not have weighing equipment in the home and/or cannot make sense of this information in the context of HF care.

3.2.4 Dyspnoea

Dyspnoea is an important symptom in chronic heart failure (CHF) which is a cause for prolonged distress for patients and carers.

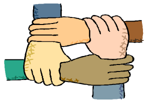
However, research is sparse and dyspnoea is rarely a target for intervention in its own right. Finding a measure to capture this remains a challenge and, despite the prevalence of this symptom, uniformity in dyspnoea measurement has not yet been achieved.

With CHF, dyspnoea varies across time and activity and affects all domains of life for patients and carers. The importance of symptoms is important however and these are subjective and can vary according to activity, mood and surroundings. This issue is beginning to be addressed in Cardiology (Johnson and Booth, 2010).

Breathless in advanced disease is covered below. The evidence shows that multidimensional treatment programmes should become widely available to support patients with advanced disease and their family caregivers in coping with the functional, psychological and social consequences of living with breathlessness (Janssen, 2015a/b).

3.3 Carer needs

3.3.1 BAME



Advice on BAME and LGBT communities has been offered in in “Education and Support for Carers of People at the EoL (completed 30th April 2015)” and it is advised that this document is consulted for detailed comments.

BAME patients may have aetiologies that are prevalent in their home region and HCPs need be aware of the risk factors for the development of HF such as hypertension and obesity - prevalent in certain ethnic groups - and should work to prevent and treat these conditions:

- Rheumatic heart disease, Chagas and coronary artery disease (CAD) should be considered in those recently arriving from South America
- Rheumatic heart disease should also be considered in patients who recently immigrated from Africa
- Diastolic HF or HF with preserved systolic function is especially common in patients of Chinese, black and Aboriginal descent.

In addition to the above, language, ethno culture, social values and potential barriers to health care specific to BAME patients with HF should be considered. Given that family and social values within BAME underlie a patient’s attitudes and beliefs toward health and disease, HCPs should undertake the following when managing BAME patients with HF:

- Ensure proper language translation is available
- Include family members in the overall management plan
- Provide medical information or educational aids in a language understood by patients or their caregivers
- Respect local traditions and be careful not to impose professionals' own values
- Work as multidisciplinary teams
- Include community health representatives, where appropriate (Howlett, McKelvie et al. 2010)

3.3.2 LGBT

In the UK, accurate numbers of people who identify themselves as lesbian, gay, bisexual or transsexual (LGBT) are hard to establish. Official figures vary between 750,000 and 3.6 million. In 2009, the number of people who had sought gender reassignment treatment was estimated at 12,500, with the expectation that this figure will grow as more transsexual people feel able to seek increasingly available support.

The National EoL Care Programme provides guidance and advice for those working with LGBT people, and for LGBT people themselves, whether giving or receiving EoL Care. The guide aims to:

- Encourage LGBT people to be confident in being open about their relationships and needs
- Guide organisations and people within them to have an LGBT-friendly culture
- Highlight constructive key messages for everyone to act upon

Section 4. Conceptual frameworks for supporting carers of HF patients

Patient education is defined as “the process of influencing patient behaviour and producing the changes in knowledge, attitudes, and skills necessary to maintain or improve health” (Yu, Chair et al. 2015). The studies identified in this EBS illustrate that certain methods of teaching are effective in HF interventions. In addition to cognitive-behavioural methods such as Motivational Interviewing (MI); to affect behavior change towards adopting a healthy lifestyle (Perk J, De Backer G et al. 2012) the following are also effective:

4.1 Health Foundation “Nudging”

Executive summary from Perry, et al, (2015) [8].

4.1.1 Background

‘Behavioural insights’ has been described as the ‘application of behavioural science to policy and practice with a focus on (but not exclusively) “automatic” processes’. Nudges are a particular type of behaviour change intervention that might be considered an expression of behavioural insights. Nudge-type interventions – approaches that steer people in certain directions while maintaining their freedom of choice – recognise that many decisions – and ensuing behaviours – are automatic and not made consciously.

Nudges have been proposed as an effective way to change behaviour and improve outcomes at lower cost than traditional tools across a range of policy areas. With health care spending rising and the NHS facing a significant funding gap, it is important to consider ways in which health care might be made more efficient and less wasteful. Given this backdrop, Ipsos MORI was commissioned by the Health Foundation to undertake a quick scoping review, supported and guided by expert interviews, to consider the evidence of and potential for the application of nudge-type interventions to health care for the purpose of improving efficiency and reducing waste.

4.1.2 Key findings

1. Nudge-type interventions with potential for changing behaviours, increasing efficiency and reducing waste in health care

Evidence around framing of health messages is often inconsistent but it may be possible to predict message effectiveness according to specific characteristics of a target audience. Framing health messages using social comparison via descriptive social norms (pointing out what is commonly done) or using injunctive norms (pointing out what is approved of) has been demonstrated to have behaviour change potential. However, both types of norm may be vulnerable to forms of ‘reactance’ leading to unintended consequences. While there is some suggestion

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[8] *This information was available on the day this EBS was due to be printed so this has been copied verbatim from the original report*

that descriptive norms may be more influential than injunctive norms, when it comes to changing health behaviours there is a lack of definitive evidence.

Information design both in terms of text and language (e.g. use of ‘plain English’ and behaviourally specific, concrete statements and presentation of risk) and appearance (e.g. colour, visual stimuli, images) may all influence how engaging or persuasive information is. There are numerous forms of health care information that might be better designed with implications for behaviour change, including clinical guidelines, discharge and handover templates, checklists, patient invitations and patient decision aids.

Prompts, cues and reminders have been demonstrated to be generally effective in changing both health care provider and health care consumer behaviours, as well as being relatively inexpensive and easy to administer. However, there is still substantial uncertainty around how best to optimise and enhance such interventions. One promising development is the adoption of other nudge principles, such as framing and planning, to enhance reminder content. However, there is currently limited evidence available.

Default options have been shown to have considerable influence on behaviours and are present across health care, in order sets, bundles and care protocols, technological prompts and communication strategies, as well as patterns of practice that are effectively ‘hidden’ defaults. The potential for application or redesign of defaults in health care is likely considerable but because they have significant behaviour change potential it is important they are designed, implemented and evaluated very carefully.

Although not strictly a nudge, financial micro-incentives have been shown to be successful in influencing some ‘one-shot’ health care consumer behaviours, such as vaccination and screening, and as part of quality improvement initiatives to improve health care provider behaviours such as hand hygiene compliance. There is some suggestion that loss-framed financial micro-incentives (i.e. those paid up front, introducing the prospect of financial loss if certain targets are not attained) may be effective but this may depend on both the audience and behaviour in question.

Evidence of the use of behavioural contracts and commitments in health care appears relatively limited. The only systematic review evidence identified indicated that there is insufficient reliable evidence to recommend routine use of contracts in health care, but some trial evidence suggests contracts can have positive effects in some settings. While contracts and commitments are potentially powerful interventions, they may suffer from two principal problems: low take-up and variable effectiveness, both of which may be addressed by other nudge-type interventions. One promising enhancement to existing contracts and commitments is to use the principle of ‘public commitment’ as a form of social consequence.

Audit and feedback interventions are generally effective, but there is still uncertainty around the specific components that make such interventions more or less effective. A set of tentative best practices derived from systematic review evidence suggests that various nudge-type interventions (notably information design, framing and specific forms of planning) may all offer ways to enhance audit and feedback.

Planning interventions, including ‘planning prompts’ (prompts to make simple plans, e.g. in the form of a paper tear-off slip) as well as more specific types of ‘self-formulated conditional plans’ such as action plans and implementation intentions, may offer a simple, cheap and effective form of nudge-type intervention across a range of behaviours. While promising, planning interventions are not guaranteed to change behaviour, and existing motivation or intention to perform a given behaviour is one of a number of factors that determine their effectiveness. Further, there is a lack of synthesised evidence summarising the effects of planning interventions with health care providers and consumers, although this gap is currently being addressed.

2. Areas of inefficiency and waste suitable for nudge-type interventions Areas of inefficiency and waste to which nudge-type interventions might be productively applied include: improved rates of medication adherence, particularly for chronic conditions

- reduction of non-attendance at health appointments and limited take-up of health care programmes such as screening
- more effective shared decision making facilitated by better patient decision aids
- reduction of overtreatment
- improved discharge and handover processes
- reduction of hospital-acquired infections
- improved evidence implementation
- effective procurement and purchase of medical devices

3. Opportunities and considerations for those developing nudge-type

This evidence review demonstrates that there are no ‘magic bullets’ when it comes to behaviour change and no one nudge-type intervention is guaranteed to work in changing health care-related behaviours. Developing effective behavior change interventions likely benefits from theory-based behavioural analysis, an appreciation of context and structured selection of possible interventions with a particular consideration of acceptability and equity.

Nudge-type interventions often comprise a number of different component parts. There is suggestive evidence that certain nudge-type interventions, e.g. audit and feedback and reminders, may offer ‘synergistic’ combinations. However, the question of what makes for effective combinations of nudge-type interventions remains largely unexplored.

There remains a gap in the evidence around the long-term impact of nudge-type interventions. Absence of evidence is not evidence of absence, but maintenance of behaviour change via nudge-type interventions is an area that might benefit from greater attention.

4.1.3 Conclusion

There is much evidence that suggests the potential for all of these nudge-type interventions to be successful if suitably applied. However, the evidence available is highly variable in terms of quality, relevance to health care and behaviour change impact. Further, even for those interventions with the strongest evidence base – prompts, cues and reminders, and audit and feedback – there is much that is not yet known about how to enhance and optimise them. There is a clear need for more good quality valuation and synthesised evidence of nudge-type interventions, their behaviour change potential and their impact on inefficiency and waste.

While nudge-type interventions hold much promise for reducing inefficiency and waste in health care it is important that intervention development clearly builds on existing research and theory. If this does not happen then nudging in health care is more likely to contribute to inefficiency and waste than reduce it (Perry et al, 2015).[9]

4.2 The transactional model of stress

The transactional stress process model developed by Lazarus and Folkman, with its emphasis on the influences of stress, appraisals, and resources, is very useful in the context of family caregiver stress and coping. In the COPE study described in page 108 for example, patient symptoms are viewed as stressors with the potential to worsen caregiver well-being. However, just as important as these stressors are the caregivers' internal resources, some of which can be affected by support and education.

The theory behind Lazarus and Folkman's model[10] in terms of understanding family caregivers' experiences is that antecedent personal and situational factors are mediated by appraising the threat they feel from the caregiving role. This then influences both their emotional responses and adaptational outcomes. Adaptational outcomes are defined as changes in social functioning, subjective well-being, and health resulting from stressful experiences. An adaptation of this theory was developed to provide the FAMQOL (see page 64) which measures QOL as an adaptational outcome. Caregiving task difficulty is a significant individual predictor for overall FAMQOL and studies of HF caregivers have found that the difficulties of HF related tasks is moderately associated with poorer mental health and significantly predicted physical health. Appraising the 'threat' involved in caring is a significant individual predictor for overall FAMQOL and psychological well-being. If education and

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[9] *This information was available on the day this EBS was due to be printed so this has been copied verbatim from the original report*

support could focus on reducing the real and perceived difficulties of tasks this could lessen the threat and potentially improve carers QOL (Nauser, et al, 2011).

The transactional model of coping is one that predominates throughout this EBS. If carers are assessed/appraised for what they need in terms of knowledge/support/barriers these needs can then be addressed in order to alleviate/educate/support them. Some of the resources in this EBS train carers to undertake nursing tasks if they so wish.

4.3 Symptom management models (SMM)

Integrated models of care based on symptom triggers rather than prognosis are recommended. For example, symptom management models (SMMs) combined with coaching strategies are useful for CVD patients and carers (Gadoud, Jenkins et al. 2013). See for example the COPE study, page 106.

4.4 Knowledge-attitude-practice (KAP)

The KAP model postulates that individuals first acquire knowledge related to a practice, and with this knowledge they develop a positive attitude towards the practice, which in turn induces behaviour changes. According to this model, the first step to changing individuals’ behaviour is to equip them with adequate and appropriate knowledge (Yu, Chair et al. 2015)**.**

4.5 Teach-back methods

This method is also known as "show me" or "closing the loop". Its aim is to ensure the understanding of the information being communicated, by asking patients to repeat back key points of the instructions. The method involves a process of questioning to determine what the patient has learned from a health education session. If there is a gap or incorrect explanation, HCPs can identify what information should be repeated. This cycle continues until the patient answers correctly. Teach-back is not a test of the learners' knowledge as much as an exploration of how

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[10] *Lazarus RS. Psychological Stress and the Coping Process. New York, NY: McGraw-Hill; 1966. 21. Lazarus RS, Folkman S. Stress, Appraisal, and Coping. New York, NY: Springer; 1984*

well the information was taught and what needs to be clarified or reviewed. Because teach-back does not require any particular level of literacy, it allows patients with low literacy levels to actively participate and for information to be reiterated. Teach-back is useful in assisting patients to understand treatment regimens and disease warning signs.

An initial review of the literature indicates that teach-back has been used as an educational strategy for health care professionals, low-income women, people with low health literacy and for patients with a chronic disease. A number of studies have targeted the use of teach-back in chronic disease education programmes to improve patients' comprehension, informed consent and reduction of readmission. However the utility of teach-back in improving adherence and self-management has not been evaluated to date (Thi Thuy, Robyn et al. 2013). This method would also be useful for BAME carers with teachers of the same language or interpreters.

4.6 Coaching

Coaching, the process of moving someone along the illness trajectory into a new situation whereby the coach helps the person identify their own resources ,strengths and potential barriers to determine and act out appropriate new behaviours. Combined with other strategies such as SMMs (above) these are very effective in helping HF patients (and their carers) in learning to monitor different symptoms and to react appropriately to their learning (Wongpiriyayothar, et al, 2011).

Some studies included self-management interventions; such as performing self-adjustment on diuretics when weight increases, and empowering patients to perform self-monitoring skills of physical signs like weight and blood pressure. Many studies have relatively short follow-up periods, used diverse medical settings and selected patient populations (i.e. excluding severe comorbidities, cognitive impairment and psychological disorders (Ditewig, Blok et al. 2010). Thus it is difficult to tease out just what is effective for HF patients and their carers. The successful interventions and resources in section 6 of this EBS, describe various interventions and resources for supporting and educating HF patients and their carers to Stay Well.

Section 5. Assessing patient potential for change

5.1 Patient Activation Measure (PAM) in the NHS in England

Engaging patients in taking a greater role in managing their health is a core element of current health and public health agendas. Patient activation describes the knowledge, skills and confidence a person has in managing their own health and healthcare and thus their potential to engage in this. Individuals with long-term conditions with higher levels of knowledge, skills and confidence understand their role in the care process and feel capable of fulfilling that role. They are also more likely to engage in positive health behaviours and to manage their health conditions more effectively.

Measuring knowledge, skills and confidence provides health providers with information it can use to re-shape its services to support people from where they currently stand. A report presented early findings from the qualitative evaluation of a range of projects that are testing different approaches to using the PAM. These projects are being run by five clinical commissioning groups (CCGs) and the UK Renal Registry. All of them aim to use the PAM as a tool to support people to be getting more involved in their health and care, and/or as a way of measuring patient involvement in their healthcare. The projects are being implemented over the course of 2014-16.

The PAM is a well-researched and validated questionnaire used to understand an individual’s attitude to their own health care. NHS England has funded the projects’ PAM licenses and is supporting shared learning, in order to understand how the PAM can help in realising the national aspirations for person-centred and personalised care in the NHS.

The Health Foundation is helping to facilitate the learning set and has joined with NHS England to fund an independent qualitative evaluation of the experience of using the PAM. A team from the University of Leicester has been commissioned to undertake the evaluation and their report presents the initial findings from their study.

The evaluation aims to:

- Understand how the PAM is being used, and how this develops over time
- Explore the impact of using the PAM in participating organisations at a range of organisational and individual levels, including perceptions and experiences of people with long term conditions
- Explicate the mechanisms of change and contextual influences on the use of the PAM
- Provide formative feedback to the learning set
- Produce generalizable, practical evidence for the future, share knowledge and learning, and disseminate findings

A description of the PAM follows with some early brief findings of this project thus far.

'Patient activation' describes the skills, confidence and knowledge a person has in managing their own health and healthcare.

Patient activation is closely linked to other concepts such as 'self-efficacy' and 'readiness to change', but patient activation is argued to be a broader and more general concept, reflecting attitudes and approaches to self-management and engagement with health and healthcare, rather than being tied to specific behaviours.

The concept of patient activation is potentially most applicable to the principles of seeking to offer care that is suitably personalised, and to supporting people to recognise and develop their own strengths and abilities.

The PAM is a measurement scale of patient activation based on patients' responses to questions which include measures of an individual's knowledge, beliefs, confidence and self-efficacy. The resulting score places a patient at one of four levels of activation, each of which reveals insight into a range of health-related characteristics, including attitudes, motivators, behaviours and outcomes.

The four levels of activation are;

- Level 1: disengaged and overwhelmed
- Level 2: becoming aware, but still struggling
- Level 3: taking action
- Level 4: maintaining behaviours and pushing further

The PAM has been translated into over 20 languages and validated in a number of them, including Dutch, Spanish and Danish.

Recent research into patient activation has demonstrated that improvements in patient activation levels can be maintained over time and are associated with better self-management and lower healthcare service use. There are three approaches to using the PAM. These are:

- intervening to improve patient engagement and outcomes
- population segmentation and risk stratification to target interventions
- measuring the performance of healthcare systems and evaluating the effectiveness of interventions to involve patients

Although it has been validated for use in the UK, little is known about how the PAM could best be implemented and used in the NHS context. NHS England is now working with six healthcare organisations to pilot the PAM, all using the PAM in different ways, across a range of approaches to improving care and supporting self-management. The Health Foundation and NHS England have commissioned a team from the University of Leicester to undertake an independent qualitative evaluation of the feasibility of using the PAM in the English healthcare context.

Early findings have been reported and, in addition, the Health Foundation's in-house data analytics team will conduct a quantitative study of the PAM use and outcomes across the six organisations will result in a mixed methods evaluation of this test phase and will inform future attempts to implement the PAM more widely.

Briefly, the findings are summarised below.

5.1.1 Role of the PAM

The approaches and projects primarily focus on one of three ways of using the PAM:

- as an outcome measure
- as a tailoring tool
- as a combination of both an outcome measure and a tailoring tool

Projects are underpinned by the following hypotheses:

- PAM scores can be used to tailor healthcare interventions at an individual level to ensure that they are appropriate, given patients' baseline levels of activation. This will result in improved intervention effectiveness, improved clinical and patient outcomes and will have a positive impact on patients' utilisation of health services.
- PAM scores can be used to tailor the provision of services in a locality based on population levels of activation. This will result in improved efficiency, cost effectiveness, and individual and population outcomes
- PAM scores can be used as outcome measures for interventions which are targeted at improving health outcomes, or at increasing patient self-management/self-efficacy. There is an implicit assumption that 'success' will be reflected in increased PAM scores.
- The PAM tool can be used as part of the consultation to change HCP behaviour, to change the nature of consultations, and to increase patient involvement and engagement in their care. This may link in with wider aims of generating cultural change towards more person-centred care, among professionals as much as among patients. This will result in improved clinical and patient outcomes, have a positive impact on healthcare utilisation, and will lead to increased patient activation (increased PAM scores).

The project will examine other factors**:**

- How the PAM is delivered and the implications of this for response rates and validity of the scores and how this will impact on the extent to which it can be effective as a tool to change health professional behaviour, to change the nature of consultations, and to increase patient involvement and engagement in their care.
- Issues and challenges

One key issue, particularly in relation to the use of PAM scores as outcome measures, relates to the risk of implicit assumptions that PAM scores would be expected to increase in a linear fashion as a result of interventions. Increases in activation are likely to be greater and easier to achieve for patients who are starting from a low score. There is also a possibility that patients may shift between PAM levels as their condition changes – for example, moving from a higher to a lower level of activation as their condition worsens. For some patients, maintaining their PAM score at their current level, rather than increasing it, may be a positive outcome for them.

A second issue relates to the risk that when patients achieve low PAM scores this may deter health professionals from investing time in attempting to engage these patients in self-management or preventative activities. It is unclear how these issues will impact on, or be taken into account by, the proposed projects, and we will remain sensitive to exploring these issues as the projects progress.

5.1.2 Planning to use the PAM

A key learning point from the work to date is the amount of time and planning required to implement the PAM in the context of existing care arrangements. Significant challenges faced by sites have included: mediated completion of PAM; working with patients whose first language is not English; gaining clinical buy-in and overcoming perceptions of PAM as a ‘tick-box exercise’; barriers arising from IT systems; and finding the time and expertise to analyse the data.

Sites have highlighted the need for piloting where possible, and have also highlighted the potential value of an approach based on staged roll out of the project with early sites acting as ‘champions’. Sites using the PAM at commissioner level have suggested that the inclusion of the PAM into service specifications can be a helpful approach.

5.1.3 Outcomes

Evidence suggests that PAM scores are predictors of health outcomes, improved service utilisation, and reduced cost. The hypotheses identified above suggest different and complex possible relationships between PAM score and other outcomes: tailoring care based on the PAM improves efficiency and outcomes; the PAM can be seen as an outcome in itself alongside other outcomes; use of the PAM in itself improves outcomes through promoting patient-centred care and involvement.

5.1.4 Projects within this study relevant to this EBS are as follows:

NHS Horsham and Mid-Sussex and NHS Crawley CCGs - Tailored Health Coaching Pilot, working with up to 2,000 patients to tailor the approach taken to health coaching, and as an outcome measure to improve self-management.

NHS Somerset CCG - West Somerset Living Better project for older adults.
Musgrove Park Hospital Patient Voices programme focused on care planning for hospital discharge.

NHS Islington CCG - Islington CCG has commissioned GP practices to offer collaborative care and support planning consultations with their patients with a list of long-term conditions including heart and atrial fibrillation.

NHS Tower Hamlets CCG

1. Esteem Self-management, led by Community Options with healthcare service provider partners, working with ~220 people with long-term conditions and mental health conditions.

2. Your Move, led by Green Candle dance company with healthcare service provider partners, working with ~55 older adults, some with long-term conditions, to improve exercise levels.

3. Managing your health and wellbeing, led by Ability Bow With healthcare service provider partners, working with ~75 people with long-term conditions or uncontrolled symptoms.

This evaluation is on-going and further results are expected.

Précised from, Armstrong et al, (2015).

https://www.england.nhs.uk/wp-content/uploads/2015/11/pam-evaluation.pdf

Section 6. Interventions and resources for staying well with HF

6.1 Effects of patient teaching, educational materials, and coaching using the telephone on dyspnoea and physical functioning among persons with HF

6.1.1 Summary

A symptom management model **(SMM)** combined with coaching strategies were used to guide the study.

A SMM has three interrelated concepts:

- symptom experience - used to guide the nurse, patient and carers to recognize and monitor HF symptoms.
- symptom management strategies - used to guide interventions or strategies to manage symptom experiences reported by individual patients
- outcomes

Outcomes were focused on eight dimensions including:

- HF symptom status
- functional status
- self-care ability
- cost
- QOL
- morbidity and comorbidity
- mortality
- emotional status

Dyspnoea severity and physical functioning were the outcomes evaluated to measure the effectiveness of the intervention. Coaching was used in this pilot study in two ways:

- An initial one-on-one education session at the cardiovascular clinic - to teach and train patients with HF on skills such as the perception of symptom experiences, identifying symptoms, and developing and enhancing symptom management strategies.
- A reinforcement of the initial education provided by using the telephone follow-up coaching sessions in patients' homes

6.1.2 Findings

- Coaching using the telephone was found to decrease dyspnoea severity and increase physical functioning
- It provided patients with problem-solving skills in recognising and closely monitoring HF symptoms, medication, diet, and fluid control
- Participants' experiences of monitoring their HF symptoms particularly dyspnoea and oedema, led to improved physical functioning
- Overall QOL scores were also significantly increased, although physical functioning did not improve, mainly because HF symptoms; such as fatigue and dyspnoea, mitigated against this
- Better performance of self-care activities to maintain health was related to better physical functioning. Also less signs and symptoms of HF were associated with better QOL

6.1.3 Conclusions

Using the telephone is familiar to most people and the initial teaching was in the patient's home. This helped patients focus on specific issues of self-management, symptom monitoring and addressed their needs and concerns; which helped to alleviate HF symptoms and increase HF self-management skills.

6.1.4 Appraisal

This pilot study showed that coaching using a telephone programme is an accessible and feasible strategy that helps patients with HF to self-manage HF symptoms, decrease dyspnoea, and improve physical functioning at home.

It was expected that the self-management skills learned would change patients' behaviours and result in the control of symptoms. (Wongpiriyayothar, et al, 2011)

6.2 Effects of a family support programme on self-care behaviours in patients with congestive HF

The aim of this small Iranian pre and post-test case and control clinical trial was to evaluate the effects of a family support intervention on the self-care behaviours in patients with HF. The supportive intervention including three educational sessions with the delivery of an educational booklet and follow-up by telephone. Results were statistically significant.

Self-care behaviour was assessed with a questionnaire.

The intervention programme included three group educational sessions with 8-12 attendees were held for each group. These sessions were held weekly for 1-1.5 hours in an appropriate classroom in the same medical educational centre.

Session 1

- Caregivers were familiarised with the definition, HF disease process, its aetiology, treatment, importance and manner of self-care behaviours and related skills such as reading food labels and taking strategies to lower food salt intake
- A booklet of HF self-care guidelines was distributed among the caregivers, to share with other family members and patients
- They were also asked to note potential questions for session 2

Session 2

- Learning and practical administration of the learned issues were evaluated
- The importance and role of family in controlling HF and patients' care was explained
- The caregivers held group discussions about living with HF patients and ways of supporting them
- In order to increase emotional and affective support toward these patients, efficient communication skills were also explained
- Case scenario, role play of suggested strategies, and supportive discussion were adopted to empower and practice learned skills
- At the end of the second session, the caregivers were given a booklet about the importance and manner of patients' practical and emotional support, and they were asked to share it with other family members

Session 3

- Caregivers shared examples of the patient supportive strategies taken, as well as prohibiting and facilitating factors they experienced
- Education about the manner of self-care as well as other related points were explained to stimulate discussion
- A contact number was given to the caregivers for HF related and self-care -related questions.

Phone call follow-ups were carried out for 2 weeks to guide the subjects and answer their questions.

6.2.1 Conclusions

One month after the group sessions and one month after the introductory test the results showed that that administration of this supportive intervention and promotion of family support led to promotion of self-care behaviour in HF patients.

Specifically, not smoking, taking the medications as prescribed, regular visits to physicians, and avoiding canned foods were among the self-care behaviours at a moderate level.

However, behaviours including daily weighing, intake of less salt, referring to a physician when observing the signs, and fluid restriction compliance were found to be poor.

Lack of daily weighing in HF is common because: people do not find it helpful, they do not have scales or they cannot interpret the results. Participants in this study were illiterate, did not have scales and considered the task of low importance.

Telephone follow up is important, knowledge alone does not appear to affect behaviour change and promote self-care. In addition to promoting caregivers' knowledge, familiarising them with supportive communication strategies to support patients emotionally was important. This facilitated the patients' to self-care along with joint education sessions.

In the present study, the highest promotion of self-care behaviour was observed after administration of the family supportive intervention in dimensions such as compliance to a low salt-diet, fluid restriction, and referring to a physician after observing the signs of disease. HF patients' families play a vital role in the control of signs and symptoms, and can help the patients to diagnose the symptoms of the disease, encourage their compliance to a medical food diet, and support them through changes in their lifestyle.

There is a positive association between family support and self-care.

The findings of the present study reveal the major and important role of family members' support in self-care among congestive HF patients. Nurses can support, educate, and guide these patients through family members' education, designing appropriate care programmes in order to take steps toward promotion of self-care (Mohsen et al, 2013).

6.3 Is ‘‘Teach-Back’’ associated with knowledge retention and hospital re-admission in hospitalised HF patients?

The aim of this study was to determine if hospitalised HF patients educated with the “teach-back” method retain self-care educational information and whether it is associated with fewer hospital readmissions.

A prospective cohort study design included 276 patients older than 65 years hospitalised with HF over a 13-month period. Patients were educated and evaluated using the teach-back method as part of usual care. Their ability to recall educational information while hospitalised and during follow-up approximately 7 days after hospital discharge was calculated. Readmissions were confirmed through follow-up telephone calls and review of medical records.

Patients correctly answered 75% of self-care teach-back questions, 84.4% of the time while hospitalised and 77.1% of the time during follow-up telephone call.

Greater time spent teaching was significantly associated with correctly answered questions. Patients who answered teach-back questions correctly while hospitalised and during follow-up had non-significant reductions in all-cause 30-day hospital readmission rates, but a trend toward significance was found in patients who had readmissions for HF.

6.3.1 Conclusions

The teach-back method is an effective method used to educate and assess learning. Patients educated for longer retained significantly more information than did patients with briefer periods of teaching.

However, correctly answered HF-specific teach-back questions were not associated with reductions in 30-day hospital readmission rates. Future studies needed to compare usual care with teach-back education (White, 2014).

6.4 A health education booklet and telephone follow-ups can improve medication adherence, health-related quality of life, and psychological status of patients with HF.

The knowledge-attitude-practice (KAP) model was the basis for this study along with a booklet and telephone reinforcement and follow-ups which aimed to help patients consolidate knowledge and skills (See page 37) (Yu, Chair et al. 2015)

Session 1 of the booklet education gives patients basic knowledge of HF:

- A brief introduction to HF and the aims of the booklet
- Normal cardiac function, HF, and how HF affects health
- Aetiology of HF and common risk factors
- NYHA classification, how HF is classified, the 6-MWT and how it is measured
- Common signs and symptoms of HF and the reasons why HF can cause each specific symptom
- Pharmacological and non-pharmacological management strategies of HF

Session 2 equips patients with appropriate knowledge of self-management when they are discharged home, i.e:

- Issues of weight monitoring: The importance of body weight monitoring, how to monitor weight, and the implications of weight change are explained and emphasised
- Kinds of symptom deteriorations which require prompt medical consultation, severe symptom exacerbations which indicate the need to call the emergency services
- Information about medication: Adherence to the medication schedule, compliance with medication, avoidance of using folk prescriptions, appropriate attitudes towards traditional Chinese medicine, and methods of dealing with adverse effects, missed medication and non-prescription drugs
- Lifestyle adjustment information: The importance of a low-salt diet, identification of high sodium foods, a low-fat diet, fluid intake, alcohol consumption, smoking, sex, driving, and working
- Issues related to exercise: Importance of exercise for cardiac patients, general principles of exercise, what kinds of exercise are acceptable, and those issues patients should pay special attention to when they are exercising
- Basic tips for patients to manage their emotions

Telephone follow-up:

- To reinforce the important points in the booklet
- To solve the problems encountered by the participants
- To supervise adherence to medication and lifestyle modification

Telephone follow-up interview guideline:

- Are there any problems you have during this week? If yes, what are they?
- Do you have your medications every day as prescribed during this week?

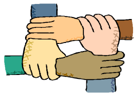
- How about your diet and exercise this week?
- Do you smoke or drink alcohol this week?
- Do you have any questions to ask?

6.4.1 Conclusions

The interventions of health education and telephone follow-up were effective in controlling the HF. The current study offers ideas for HCPS to develop interventions while undertaking clinical work with limited resources.

Providing health education using a booklet tailored to patients' information needs together with telephone follow-ups can effectively improve patients' outcomes and help them to maintain a degree of physical, psychological, and social well-being when living with HF.

6.5 Integrated primary care for patients with mental and physical multi morbidity: a cluster randomised controlled trial of collaborative care for patients with depression comorbid with diabetes or cardiovascular disease. CLAHRC Greater Manchester



This randomised control trial (RCT) tested the effectiveness of an integrated collaborative care model for people with depression and long term physical conditions with 36 general practices and 387 patients with a record of diabetes or heart disease, or both, who had depressive symptoms for at least two weeks in the North West of England.

"Collaborative care" is a complex intervention that involves the use of a non-medical case manager working in conjunction with the patient's physician (usually their primary care physician), often with the support and supervision of a mental health specialist (normally a psychiatrist or psychologist).

Collaborative care included:

- patient preference for behavioural activation
- cognitive restructuring
- graded exposure

- lifestyle advice
- management of drug treatment
- prevention of relapse

Treatment involved:

- Up to eight sessions of psychological treatment delivered by specially trained psychological wellbeing practitioners employed by Improving Access to Psychological Therapy (IAPT) services in the English National Health Service
- Integration of care was enhanced by two of these treatment sessions delivered jointly with the practice
- Nurse. Practice Nurses were Introduced to the COINCIDE care model with an emphasis on effective liaison and delivering integrated physical and mental health care
- A 10 minute collaborative meeting (by telephone or in person) between the patient and the psychological wellbeing practitioner and a practice nurse from the patient's general practice was scheduled to take place at the end of the second and eighth sessions
- Usual care was standard clinical practice provided by general practitioners and practice nurses

The primary outcome was reduction in symptoms of depression on the self-reported symptom checklist four months after baseline assessment

Secondary outcomes included:

- anxiety symptoms
- self-management
- disability
- global quality of life

6.5.1 Results

- After adjustment for baseline depression score, mean depressive scores were points lower in the collaborative care arm. They also reported significantly less anxiety at follow- up
- Patients in the intervention arm also reported being better self-managers, rated their care as more patient centred, and were more satisfied with their care
- However, there were no significant differences between groups in quality of life, disease specific quality of life, self-efficacy, disability, and social support

- Treatment effects for depression are modest. However, they were achieved in the context of a pragmatic trial that included participants with considerable levels of mental and physical multi morbidity and high levels of socioeconomic deprivation
- Participants in the collaborative care arm rated the delivery and experience of care as more patient centred

6.5.2 Conclusions

Collaborative care that incorporates brief low intensity psychological therapy delivered in partnership with practice nurses in primary care can reduce depression and improve self-management of chronic disease in people with mental and physical multi morbidity.

A patient information (PI) sheet was included in Urdu and Gujarati and information sheets and consent forms were also translated. A researcher fluent in Urdu, Hindi, and Punjabi telephoned eligible patients of South Asian origin who did not speak English to provide further information about the study. 15% of this sample was from the BAME community.

Notwithstanding that treatments effects were modest compared to other trials which have achieved more significant findings over a longer follow up, COINCIDE tested a broader range of psychological treatments (that is, behavioural activation, cognitive restructuring, graded exposure, and lifestyle approaches, with the option to stay or start taking antidepressants), specifically tailored to meet the needs of patients with long term conditions, thus enhancing the integration of physical and mental healthcare.

There is no definitive evidence about the mechanisms or moderators that led to improved depression outcomes in this trial. It could have been the high level of integration between mental and physical healthcare providers. On the other hand, the positive effects for depression could have been attributable to the presence of the psychological wellbeing practitioner only and not the collaborative framework.

The COINCIDE trial is a test case of how a brief and integrated collaborative care model can be rolled out at a pace and scale within the normal context of chronic disease management by using existing providers and without greatly altering arrangements for clinical supervision.

The COINCIDE model is being taken up in the Increasing Access to Psychological Therapy (IAPT) initiative as part of a phased National Institute for Health Research funded roll out and evaluation of collaborative care for people with long term conditions and common mental health problems

6.5.3 Resources

All of the COINCIDE resources are available for the MYMC project team to access; these can be obtained from:
CLAHRC Greater Manchester
3rd Floor, Mayo Building

Salford Royal NHS Foundation Trust
Tel: 0161 206 8551
Email: clahrc@srft.nhs.uk
Web: http://clahrc-gm.nihr.ac.uk/

6.6 Big Life Centre Greater Manchester

Aims

To improve health and wellbeing for people with multiple lifestyle risks (smoking, alcohol, lack of activity, overweight, low mood). Includes people with LTCs. Primary outcome is increasing self-efficacy and also indicators relating to personal goals, wellbeing and the above lifestyle issues.

Objectives

- To improve self-efficacy of individuals.
- To reduce multiple lifestyle risk factors. To reduce health inequalities

Theoretical Framework

Based on a theory of change model incorporating evidence for behaviour change, particularly self-efficacy and how skills are built

Types of support provided includes:

- Face to face (one to one)
- Face to face (Group)
- Telephone
- Online

Intervention delivery methods include:

- Face to face (one to one)
- Face to face (group)
- Telephone

The intervention is delivered by:

- Lay people
- Professionals

This intervention uses the QISMET (quality institute for self-management education and training) 2015 standard for self-management providers

https://www.thebiglifegroup.com/

6.7 Web based education

6.7.1 HF society of America

http://www.hfsa.org/

The HF Society of America, Inc. (HFSA) is a forum for researchers and clinicians with an interest in heart function, HF, and Congestive HF (CHF) research and patient care.

The site is mainly aimed at people living in US but it has a patient's section, which is useful for patients anywhere in the world, where they can learn more about HF and how to manage it. This area has a series of 11 education modules in the form of puff booklets that can be downloaded for free.

The modules comprise:

- Module 1. Taking control of your HF
- Module 2. How to follow a low sodium diet
- Module 3. HF Medicines
- Module 4. Self-care following your treatment plan and dealing with your symptoms
- Module 5. Exercise and activity with HF
- Module 6. Managing feelings about HF
- Module 7. Tips for family and friends about HF. These are tips for family and friends focus on specific things that family members and friends can do to help a person with advanced/severe HF. It covers the following:

    - Recognising changes in symptoms
    - Following a low-sodium diet
    - Becoming more active
    - Remaining independent but safe
    - It will help family and friends learn
    - Why support is a vital part of a HF treatment plan
    - How to increase the overall level of support the person with HF receives
    - How to promote good self-care behaviours
- Module 8. Lifestyle changes. Managing other chronic conditions
- Module 9. Advance Care Planning
- Module 10. Heart rhythm problems
- Module 11. How to evaluate claims of new HF treatments and cures

6.8.4 Heart Failure Matters

http://www.heartfailurematters.org/

Contains information about a wide range of different HF related topics for both patients, HCPs and carers (see below)

Understanding HF	**Living with HF**
What can your doctor do	Lifestyle
What can you do	Travel
Adapting your lifestyle	Driving
Managing your medicines	Work
Immunisations	Immunisations
Taking your own blood pressure and pulse	Relationships
Support groups	Your emotions
Keeping other medical conditions under control	Managing your medicines
	Support
	Planning for the End of Life

For caregivers
- Understanding your role
- Simple things you can do to help
- Understanding their emotions
- How you may be feeling
- Support Networks
- Financial concerns
- Planning for the future
- Warning signs

Ask your doctor
- My medicines
- Devices
- Surgery
- Tests and procedures
- Living with HF
- Relationships and emotions
- Caregiving
- Planning for the future
- Getting support

6.8 Written information

6.8.1 “Taking care of myself: a guide for when I leave the hospital”

A booklet for patients and carers. It contains proformas for HCPs to enter:

- Prescribed medications, reasons for these and what time of day they should be taken
- Dietary advice
- Exercise
- Hospital visits

The booklet also includes proformas to write down questions to ask at a consultation, i.e. about medications, test results, pain, feeling stress or other concerns. It aims to:

- stimulate discussion at HCP visit/appointments
- act as a modus operandi at home
- help with self-care
- be helpful to family and carers

Appraisal

This is a simple notebook which could be useful for many patients who are on complex medical regimens to record information about what medicines are taken for what symptoms and for medical appointments.

Resource
http://www.ahrq.gov/patients-consumers/diagnosis-treatment/hospitals-clinics/goinghome/index.html

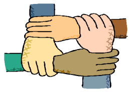
6.8.2 British heart foundation (BHF) resources

"Caring for someone with a heart condition"
https://www.bhf.org.uk/heart-health/living-with-a-heart-condition/caring-for-a-heart-patient

Contents include:

- Are you a carer?
- What has happened to the person you're looking after?
- Tests and treatment
- Becoming the carer
- Preventing further heart problems
- Getting back to normal and encouraging independence
- Sexual activity
- Financial help and carers' assessments
- The emotional aspects of being a carer
- Heart attack? The symptoms … and what to do
- Cardiac arrest? The symptoms … and what to do

"Living with HF"
https://www.bhf.org.uk/publications/heart-conditions/living-with-heart-failure



Headings include:

- What is HF?
- What causes HF?
- What are the signs and symptoms of HF?
- How is HF diagnosed?
- What is the treatment for HF?
- Medicines to treat HF
- What you can do to help yourself
- Surgery and other treatments
- Everyday life with HF
- If your HF gets worse
- Caring for someone with HF
- What to do if someone has a heart attack or cardiac arrest

Appraisal

This booklet was very clear and honest about what having HF entails and the uncertainty of the prognosis attached to this condition. With a diagram of the heart, it explains the different classes of HF and Cardiac resynchronisation therapy, implantable cardioverter defibrillator (ICD) - although not the implications of removing these near the end of life, Left ventricular assist device (LVAD) and also addresses palliative care. Read alongside "Caring for someone with a heart condition" (page **Error! Bookmark not defined.**). Both booklets offer practical information for patients and carers

For people of South Asian origin, a booklet "HF - Information for South Asians" is available in Bengali, Gujarati, Hindi, Punjabi, Urdu and English.

Order line on 0870 600 6566, or email: orderline@bhf.org.uk, or visit www.bhf.org.uk/publications

“An everyday guide to living with HF: a personal record”
https://www.bhf.org.uk/publications/heart-conditions/an-everyday-guide-to-living-with-heart-failure

This personal record is designed to be used by patients and carers. It is designed for people keep all the important notes about their HF symptoms, medication and treatment in one place and helps them and HCPs track their progress. The booklet contains proformas for information to be recorded such as:

Daily fluid, weight, medication (when to take, what for, strength etc.) heart rate, blood pressure, heart tracing, exercise tolerance, paroxysmal nocturnal dyspnoea (waking up suddenly short of breath/panicky), the number of pillows slept on at night, Oedema swelling, New York Heart Association score (1,2,3,4) & JVP Jugular venous pressure

email orderline@bhf.org.uk or call 0870 600 6566 and quote G275A.

“Heart to heart: Heart disease and your emotional health”
https://www.bhf.org.uk/publications/living-with-a-heart-condition/heart-to-heart---heart-disease-and-your-emotional-wellbeing

Contents include:

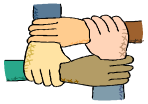
- How can I boost my wellbeing?
- Stress and heart health
- Cardiac rehabilitation
- What stops us talking about emotional health?
- How can I tell when I need more help?
- Thoughts about ending it all
- How can I explain to my GP?
- What might help me?
- Self-help
- Counselling and other talking therapies
- Medication
- Going back to work
- For partners, family and friends
- How can I help my loved one?

- What about professional help?
- How can I help my loved one with their treatment?

Appraisal

This is a very elegant booklet. It is easy to read and uses mixed media in order to keep people engaged with its contents (colour, speech bites, photographs, examples & text). The contents pages are clear and the information on each chapter topic is extremely useful. Within each chapter there is a personal story about someone along with their photograph and where they live. This serves to place their heart related issues into the real life context of living with HD on a daily basis. Although this booklet is also aimed at people who can return to work, it remains an excellent resource for all HF patients and families

6.8.3 Scottish Intercollegiate Guidelines (SIGN) Chronic HF



This booklet is for people with Chronic HF and for their families and friends. It is evidence based from a national clinical guideline on how to look after patients with Chronic HF. The booklet aims to inform patients of the tests and treatment they should expect to receive from the NHS.

Chapter titles are:

- what chronic HF is
- what causes it
- what the symptoms are
- how it is diagnosed
- how it is treated
- what you can do to help yourself - lifestyle changes
- how will I feel?
- medicines for Chronic HF
- other treatments
- leaving hospital
- information and support
- glossary

Appraisal

This booklet is excellent. It is clear, describes everything a patient and carer need to know and addresses the issues of death and EoL Care. It explains the New York Heart Association (NYHA) scale and how the severity of HF is measured and classified 1 – 1V. Technical terms used based on BHF definitions are explained and is a very accessible and readable booklet (21pp).

The booklet is currently being updated in relation to clinical guideline recommendations.

The booklet is available from http://www.sign.ac.uk/pdf/pat95.pdf and in Urdu and can be downloaded from http://www.sign.ac.uk/pdf/pat95urdu.pdf

6.9 Films

6.9.1 "So you have been diagnosed with HF" - from "Pilot testing of a self-care education intervention for patients with HF (Boyde, Song et al. 2013)

A small pilot study tested an educational intervention - a self-care manual combined with a DVD. Outcomes included HF related knowledge and self-care behaviours.

Knowledge was assessed with the Dutch HF knowledge:

- Scale and self-care behaviours were assessed using the Self-care of HF Index.
- There was a statistically significantly difference in the pre- and post-test scores for knowledge
- Self-care showed positive improvement between pre- and post-test scores; maintenance management

This pilot study has indicated that a patient-centred self-care manual combined with a DVD is beneficial and associated with an improvement in patients' knowledge and self-care abilities.

Another on-going RCT using 200 patients produced the manual and a DVD. Although these resources do have copyright the DVD is accessible through the link below to share with patients and families.

http://www.heartonline.org.au/resources/videos/so-youve-been-diagnosed-with-heart-failure

Appraisal

This Australian DVD comprises a number of different 'scenes' all of which are self-contained films and some information is repeated in each. However, this serves to reinforce main messages. The film begins with an introduction by a GP explaining HF, its consequences and how it can be managed.

Scenes are based on a patient 'Doug' and his wife although they do not have a 'voice' over and above the film narration on the lived experience of HF. The main focus in the film is on strategies to live longer and improve heart health although it is made clear in the film that there is no cure for HF and prognoses are variable. There is advice for both patients and families about the daily management of symptoms and how to address emotional reactions and health with a focus on depression.

6.9.2 One step at a time - living with HF" (BHF)

https://www.bhf.org.uk/heart-health/living-with-a-heart-condition/living-with-heart-failure

A copy of this 55 minute long DVD has been provided to the MHMC team to accompany this EBS

6.9.3 "What is self-management" (The Health Foundation person centred resources centre)

http://personcentredcare.health.org.uk/resources?f[0]=field_resource_type%3A35&f[1]=field_area_of_care%3A359
There are three films that have been produced, all of these have been reviewed by the Health Foundation. Although they are believed to be of the highest possible standard the Health FOundation does not take responsibility for the accuracy of the information. Examples from this site are:

Resource one Self-Management Support – explanatory video clip.

In this 10 minute video clip clinicians and service users set out the benefits of supporting people to manage their own condition and the key components of self-management support.

Author:
South West London & St George's Mental Health Trust

Resource two "What is self-management?"

Developed by a company called Know Your Own Health this four minute video clip is in cartoon form and provides a brief and entertaining introduction to the principles of self-management and how it can support people managing long term conditions.

Author:
Know Your Own Health

Resource three "What is self-management?"

This two-minute video aimed at patients briefly sets out what self-management means from a patient perspective.

Author:
Self-management

6.10 Measure for carers quality of life (FAMQOL)

FAMQOL is a short 16-item instrument that measures overall caregiver QOL and has been tested with HF family caregivers. The domains of physical, psychological, social, and spiritual well-being are represented equally with 4 items each.

The FAMQOL has been evaluated for content validity by seven experts including carers. The item pool was reviewed by five doctoral prepared nurses with backgrounds in HF or family caregiver research, an adult child HF caregiver, and a spousal HF caregiver.

Rather than a generic measure, a family caregiver specific instrument may be more precise in measuring HF family caregiver's QOL.

Threat appraisal was a significant individual predictor for overall FAMQOL and psychological well-being,

Task difficulty is associated with poorer mental health and significantly predicts physical health supporting the use of Lazarus' transactional theory of stress. See page 3633. (Nauser, et al. 2011)

6.10.1 Appraisal

This would be a useful measure for the MHMC project team to use. The author would welcome feedback on its usefulness. Permission has been granted from Nauser to use the FAMQOL; and a copy has been sent to the MHMC project team.

Section 7. Web based information

Two 2009 investigations of HF informational material on Internet websites found that a biomedical approach was prevalent. Information was often written in the third person and presented in an authoritarian manner using technical language. Less evident was a partnership approach that provided information about living with HF. Where this occurred, it was generally written in the second-person and focused on the experience of HF. An evaluation of 15 websites revealed only five that included all required areas of content, together with a readability score at or near the appropriate level for most patients. Thus it is a major challenge for HCPs to identify websites that are credible, reader-friendly, and provide quality material, and so that patients do not feel overwhelmed. Research investigating the use of an iPad app to support self-care and monitoring is currently underway, with some initial promising results (Boyde and Peters 2014). Major HF sites are described and reviewed below.

7.1 British cardiac patients association

The organisation operates a national helpline (01223 846845) to discuss any concerns or worries. Operators have been patients or carers.

There is a range of factsheets containing useful stats, explanation of the disease and advice on how to manage the disease and improve health, all explained in lay terms. Similarly, they publish a Glossary with Heart Disease related terms. These resources can be downloaded from the website.

A bi-monthly journal magazine, BCPA Journal, is available for members, which contains dietary advice, recipes, events around the country, patient's histories and articles about interventions performance and developments. Some issues are available to be downloaded free from the website.

There are links to sites that provide clinical information (NHS National Library for Health, Hearts for Life), advocacy groups (Heart Valve Voice) or health and lifestyle advice (Counselling Directory, MedictDirect, Anticoagulation Europe, Transplant Support Network).

www.bcpa.co.uk

7.1.2 Contact details

BCPA Head Office
2 Station Road

Swavesey
Cambridge
CB4 5QJ

Phone: 0800 479 2800
Fax: 01954 202 022
Email: enquiries@bcpa.co.uk

7.2 British Heart Foundation - Carer resources and information

The main area of the website that provides information to patients and carers is Heart health. This page has links to information about how the heart works, prevention, tests, treatments, the different heart conditions and living with a heart condition.

Within the living with a heart condition page there is a link to the cardiac rehabilitation page, where information on how does cardiac rehabilitation help and who is it for are given. In this are there are links to BHF booklets with relevant information, such as:

- Cardiac rehabilitation booklet : It explains what cardiac rehabilitation is, how you can help your recovery in the first few weeks and what happens on a cardiac rehabilitation programme and what you can do to keep your heart healthy.
- Lifelines - heart surgery and after: This programme follows five patients with coronary arterial disease or requiring valve replacement through three key stages: preparing for heart surgery, what to expect in hospital and recovery.

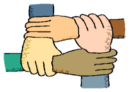
These booklets, as any other BHF materials, can be downloaded or printed versions can be ordered for free.

The website also offers a link for carers. Caring for a heart patient where information on caring for a heart patient and for oneself is provided. The booklet Caring for someone with a heart condition contains practical information, such as financial help carers may be entitled to, emotional aspects of being a carer and how to cope if things get difficult. It also includes details of organisations that are able to provide carers with support.

Another booklet that might be helpful is Medicines for your heart. It describes some of the different medicines often prescribed for people with a heart condition. It also covers medicines used to control high blood pressure or high cholesterol levels. The booklet explains why the medicine has been prescribed, how it works and possible side effects.

Take heart - our heart health information for you and your loved ones is a catalogue listing all of the heart health information produced by BHF

7.3 British society for heart failure



http://www.bsh.org.uk/patients/basics/

Pages on:

- What is HF?
- Causes of HF
- Symptoms of HF

Books and pamphlets

- Everyday guide to living with HF
- Byw gyda methiant y galon (Living with HF - Welsh language version)
- One step at a time - living with HF
- Difficult conversations - making it easier to talk to people with HF about the End of Life
- Caring for someone with a heart condition
- Keep your heart healthy - Polish
- Keep your heart healthy - Welsh
- Heart Attack - Welsh
- Angina - Welsh
- Looking after your heart - Gujarati, Hindi, Punjabi, Urdu (not located as of 29/10/15)
- Smoking shisha & chewing tobacco how to stop (not located as of 29/10/15)
- Life with Hypertrophic cardiomyopathy
- Life with Dilated cardiomyopathy
- Arrhythmogenic right ventricular cardiomyopathy

Patient groups

- British Heart Foundation (BHF)
- Cardiomyopathy Association
- Congestive HF Community
- Congestive HF Online Support Group
- HF Support Group
- Nuffield Department of Primary Care Health Sciences - monitoring long-term conditions in primary care
- Revolution Health
- The Pumping Marvellous Foundation (For HF patients and carers to help understand and use knowledge to manage the condition. Also promotes symptoms of HF to the public and HCPs to detect this early

Section 8. Recommendations for support and education for staying well with HF

Although self-management is receiving more attention as an effective approach for patients to manage their conditions, not much is known about which particular outcomes are valued by patients and their families, HCPs and commissioners.

To date, there is limited research evaluating effects of psycho-educational interventions, many reporting neutral effects, despite having included structured education and individualised support requested by carers (Stromberg 2013). HF Management Programmes have been proven beneficial in assisting HF patients in overcoming difficulties, with patient education identified as an essential component of care in this cohort by key organisations including the European Society of Cardiology, the American College of Cardiology/American Heart Association, and the National Heart Foundation of Australia/Cardiac Society of Australia and New Zealand (Boyde and Peters 2014).

Education of HF patients is complex and multifaceted, and to date there is no definitive gold-standard approach. ‘Bundling’ various educational strategies and materials together in an attempt to achieve incremental benefits has resulted in compromising efforts to determine the effect of any single strategy. Other bundled approaches, including the use of tele-monitoring, interactive voice response reminder systems, and computer-aided learning, have also produced varying results (Boyde and Peters 2014). If an intervention and the follow up period is too short, this can show no effects however (Agren, Evangelista et al. 2010).

This evidence serves to indicate that patient and carer strategies and education should be individualised after gaining a full understanding of the relational dynamics within the dyad and their families (Buck, Zambroski et al. 2013) (Bos-Touwen et al, 2015). Patient characteristics that are normally associated with poor self-management capacity do not necessarily influence the effectiveness of a given intervention (i.e. age, gender, ethnicity, disease severity, number of comorbidities). Characteristics such as low income, literacy, education, baseline self-management capacity has been known to *increase* the success of interventions (Bos-Touwen, et al, 2015).

Patient education is defined as a process of influencing patient behaviour and eliciting the changes in knowledge, attitudes, and skills necessary to maintain or improve health (Yu, Chair et al. 2015). It can positively influence attitudes and behaviours and improve health outcomes (Srisuk, Cameron et al. 2014) (Yu, Chair et al. 2015). Simple knowledge-attitude-practice (KAP) models postulate that individuals first acquire knowledge related to a practice, and with this knowledge they develop a positive attitude towards the practice, which in turn induces behaviour changes, the first step being to equip patients and carers with adequate and appropriate knowledge (Yu, Chair et al. 2015). In relation to HF situation, patient education can motivate patients’ adherence to treatment and lifestyle changes. The evidence-base in support of patient education improving HF health outcomes has resulted in the inclusion of educational strategies as a key non-pharmacological component within evidenced-based HF practice guidelines (Srisuk, et al. 2014).

There appears to be a lack of information about certain topics, such as anaemia and cognitive problems for HF patients.

Interventions should aim at:

- Having a Specialised HCPs should be involved whenever necessary (Perk J, De Backer G et al. 2012)
- Using individualised, combined multimedia patient education materials
- Providing multiple one-on-one sessions (Boyde and Peters 2014)
    - providing very frequent professional contact during a long time period (Buck, Zambroski et al. 2013, Stromberg 2013) (Agren, Evangelista et al. 2010)
    - defining what is meant by a) self-management and b) the conceptual framework used behind these interventions (Ditewig, Blok et al. 2010)
- Ascertaining literacy and health literacy
- Using proven methods of delivering education including assessing learning needs and style
- Having a partner/family-centred approach (Agren, Evangelista et al. 2010, Buck, Zambroski et al. 2013)(Shahriari, et al, 2013)
- Verbal interaction with a HCP (Boyde and Peters 2014)

It must be borne in mind by HCPs that some people do not want to care and in terms of staying well the care/family should acknowledge their limitations or their role as part of the care pathway. To overstep this would likely only serve to increase their stress (E.I.G.E. 9)

8.1 Guidelines for developing printed education material - adapted from (Boyde and Peters 2014)[11]

8.1.1 Design

- Use a short title
- Ensure that the purpose of the printed material is clear to the intended reader
- Use at least a 12-point type font
- Write in the active voice
- Aim for year/grade 5 to 6 reading level

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[11] *This article is attached to the electronic version of this EBS*

8.1.2 Content

- Keep content clear, simple, and concise
- Use common language
- Include a table of contents
- Outline the learning objectives
- Use topic headings
- Use one- and two-syllable words understood by the intended reader
- Use short sentences, with one idea to a sentence
- Use short paragraphs and discuss important ideas first
- Ensure that the content is focused on what the reader should do
- Provide examples
- Include questions
- Avoid jargon and define medical terminology
- Ensure that content is based on the information needs of the target audience
- Ensure that content is evidenced-based
- Ensure currency by including a publication date
- Acknowledge sources of information

8.1.3 Layout

- Use a structured format with clear and obvious headings
- Use bold print to highlight headings
- Use subheadings
- Use bullet points
- Use upper- and lower-case letters for ease of reading

8.1.4 Presentation

- Use adequate spacing, with adequate white space
- Use dark print on light background
- Use illustrations that are recognisable, clearly labelled, informative and complementary to the written text

Section 9 Curriculum suggestion for carer education with guidelines & support for staying well with HF

Table 4 Curriculum suggestions for carer education & support for staying well with HF

GENERAL ISSUES		
CARER TASK/ISSUE	**STRATEGIES, GUIDELINES, KNOWLEDGE**	**SUPPORT/EDUCATIONAL PROGRAMMES/RESOURCES**
Differential diagnosis Differences in the prevalence of risk factors and comorbidities in patients with reduced (systolic HF) compared with normal (diastolic) HF. (Chinali, M et al, 2010)	Patients with diastolic HF are more likely to be older, female, obese, and to have higher systolic blood pressures and lower heart rates at the time of hospital presentation than patients with systolic HF. The strongest metabolic correlates of diastolic HF were obesity, hypertension, and clustered metabolic risk factors. Patients with systolic HF had a greater prevalence of diabetes, previous myocardial infarction, and a history of alcohol abuse as compared with patients with diastolic HF. In multivariate analyses; diabetes was associated with the occurrence of systolic HF.	Multiple risk factors and comorbidities are present in patients with systolic and diastolic HF. Consideration of these comorbidities and risk factors should be taken into account in distinguishing patients with diastolic HF from those with systolic HF and in their optimal management.
Knowledge of the HF trajectory and medical terminology "the course of HF is exceptional in its unpredictability, and for an individual patient, no specific trajectory can be	**Carers require guidance on best practice care** (Ivany, E, 2015) **NICE GUIDELINES108**: **INFORMATION FOR THE PUBLIC** Chronic HF: Management of chronic HF in adults in primary and secondary care This site attempts to simplify the guidelines for	Pilot testing of a self-care education intervention for patients with HF (page 62) **The COPE study (Creativity, Optimism, Planning, and Expert Information)** Page 108 **Patient booklet** **Chronic HF** SIGN (SCOTTISH INTERCOLLEGIATE GUIDELINES)

reliably anticipated" (Connolly, Beattie et al. 2014) Knowledge about HF was described by partners as important for managing the caregiver role (Agren, Evangelista et al. 2010)	carers and patients in terms of what information and care to expect and what is required from Healthcare. Medical words and terms should be explained, i.e: What is HF? What causes HF? Symptoms of HF Types of HF Chronic HF Defibrillator Echocardiogram Electrocardiogram HF due to left ventricular systolic dysfunction HF with preserved ejection fraction Myocardial infarction Pacemaker Serum natriuretic peptides Diagnosis of HF If you've had a heart attack in the past If you've not had a heart attack in the past Tests to rule out conditions with symptoms similar to HF Reviewing the diagnosis Treatments for HF Lifestyle Drug treatment Other treatments Rehabilitation http://www.nice.org.uk/guidance/cg108/ifp/chapter/Your-care	NHS quality improvement Scotland see page 60 above and for all refs for this resource below **REACH II.** Section on explaining terminology **DVD** "So you have been diagnosed with HF" See page 62 for appraisal **BHF Booklet "Living with HF"** page 58)

CARER TASK/ISSUE	STRATEGIES, GUIDELINES, KNOWLEDGE	SUPPORT/EDUCATIONAL PROGRAMMES/RESOURCES
Carer assessment/ support/ health	**Relaxation techniques** **Spiritual care** **Exercise**	**Beyond Blue** Reduce Stress handout Sleep well handout

Caregivers of those with HF are challenged with facing a long term burden involving significant day to day life changes, potentially leading to poor mental and/or physical health, limitations in daily life, isolation, loneliness and a lack of sufficient social and professional support. **Carers require greater social support** One of the most negative outcomes of caregiving is having less time for activities with friends (Agren, Evangelista et al. 2010).	**Relationship building** **NICE Guidelines on Chronic HF: Management of chronic HF in adults in primary and secondary care:** **1.5.7 Support groups** Healthcare professionals should be aware of local cardiac support networks and provide this information to patients and carers. [2003] https://www.nice.org.uk/guidance/cg108	http://www.beyondblue.org.au/ **BOOST** A free 6 week course for improving mental wellbeing for the public. Report of the delivery and development of the Boost course in Manchester 2012-2013 Manchester Mental Health and Social Care NHS Trust (Wood and Drummond, 2013). **COPE study (**page 106) **REACH II** **BHF Booklet “Living with HF”** (page 58) **Family Quality of Life Measure** 16 Item FAMQOL Nauser, J. A. et al (2011). See page 74 above. PHQ-9 Depression screening tool Nauser, J. A. et al (2011).

CARER TASK/ISSUE	STRATEGIES, GUIDELINES, KNOWLEDGE	SUPPORT/EDUCATIONAL PROGRAMMES/RESOURCES
Vigilance/monitoring for change Signs carers need to look out for include: • shortness of breath that is not related to usual exercise or activity • increased swelling of	Constant vigilance for alterations in symptoms is a significant task. Nearly half of partners of HF patients felt that they had to be available for their partner 24 hours a day which is a significant responsibility and can result in their social isolation (Hwang, Luttik et al. 2010). Carers can watch out for warning signs that a person's HF is getting worse, or if they are not responding to treatment. They can also provide the doctor with additional information or insights into the	**COPE study** (page 106) **Patient booklet** **Chronic HF** SIGN (SCOTTISH INTERCOLLEGIATE GUIDELINES) NHS quality improvement Scotland Page 60 **BHF Booklet “Living with HF”** (page 58) **DVD**

the legs or ankles - weight gain of more than 1.8 to 2.3kg (4 to 5lb) over a few days - swelling or pain in the abdomen (tummy) - trouble sleeping or waking up short of breath - **a dry, hacking cough** - increasing tiredness or feeling tired all the time (Connolly, Beattie et al. 2014)	person's condition, which can be helpful for planning the right treatment. (Connolly, Beattie et al. 2014) http://www.nhs.uk/conditions/heart-failure/pages/living-with.aspx	**"So you have been diagnosed with HF"** See page 62 for appraisal
CARER TASK/ISSUE	**STRATEGIES, GUIDELINES, KNOWLEDGE**	**SUPPORT/EDUCATIONAL PROGRAMMES/RESOURCES**
Emergency admissions/discharge home Patients having recurrent emergency admissions or recently being discharged home can increase a carer's burden. (Whittingham, Barnes et al. 2013)	All patients with cardiovascular disease must be discharged from hospital with clear guideline-oriented treatment recommendations to minimise adverse events (Perk J, De Backer G et al. 2012). Transferring from hospital to home. New guideline launched 1 December 2015. A new NICE guideline focuses on what should happen in hospital, from admission onwards and throughout someone's stay, so that their discharge isn't rushed or unplanned. The guideline, developed by the NICE Collaborating Centre for Social Care - a partnership led by SCIE, ensures people with social care needs get the support they need to leave hospital and prevent delayed discharge from care. SCIE is keen to encourage good collaboration	**COPE study** (page 106) **Patient booklet** **Chronic HF** SIGN (SCOTTISH INTERCOLLEGIATE GUIDELINES) NHS quality improvement Scotland Page 60 **Booklet** **Taking Care of Myself: A Guide for When I Leave the Hospital** April 2010 Page 56

	between health and social care. People’s experience of transition between hospital and home is a key indicator on how well integration is working. • Transition between inpatient hospital settings and community or care home settings for adults with social care needs • SCIE's integration resources and consultancy services • NICE Collaborating Centre for Social Care http://www.scie.org.uk/news/?utm_campaign=6367467_SCIE%20E%20Bulletin%2001%20dec%2015&utm_medium=email&utm_source=SCIE&utm_sfid=003G000002FF4txIAD&utm_role=&dm_i=4O5,3SH63,KSTGKS,DNNK2,1 NICE Guidelines on Chronic HF: Management of chronic HF in adults in primary and secondary care 1.5.2 Discharge planning • Timing of discharge should take into account patient and carer wishes, and the level of care and support that can be provided in the community • The primary care team, patient and carer must be aware of the management plan • Clear instructions should be given as to how the patient/carer can access advice, particularly in the high-risk period immediately following discharge • Management plans for patients with HF should be discussed with non-NHS agencies where they are involved in or responsible for the care of a person with HF	

	• The principles of pharmacological management for a patient cared for in a non-NHS institution should be similar to those for any other patient with HF • The education needs of non NHS carers should be considered https://www.nice.org.uk/guidance/cg108[12]	
CARER TASK/ ISSUE	**STRATEGIES, GUIDELINES, KNOWLEDGE**	**SUPPORT/EDUCATIONAL PROGRAMMES/RESOURCES**
Communication issues with HCPs **NICE Guidelines on Chronic HF: Management of chronic HF in adults in primary and secondary care:** ***1*.5.5 Communication** Good communication between healthcare professionals and patients and carers is essential for the best management of HF. **Assess patient and carer health literacy (Boyde and Peters 2014)**	Carers can expect that HCPs: • Listen to patients and respect their views and beliefs • Give patients the information they ask for or need about their condition, its treatment and prognosis, in a way they can understand including information about any serious side effects of drugs to be prescribed • Provide the most important information first • Explain how each item will affect patients personally • Present information in separate categories • Make advice specific, detailed and concrete • Use words the patients will understand; confirm understanding by questions; define unfamiliar words; write down key words; draw diagrams and keep a copy in the medical notes • Repeat the information using the same words each time • Prepare material, written or taped, to back up handwritten notes • Share information with patients' partners, close relatives or carers if they ask you to do so. When	**REACH II.** page 124 **Patient booklet** **Chronic HF** SIGN (SCOTTISH INTERCOLLEGIATE GUIDELINES) NHS quality improvement Scotland Page 60

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[12] *This guidance updates and replaces some of the 'Chronic HF' (NICE clinical guideline 5. (2003).*

	patients cannot indicate their consent for such sharing of information, it is advisable to share the information that those close to the patient need or want to know, except where you have reason to believe that the patient would object if able to do so • The content, style and timing of information provision should be tailored to the needs of the individual patient. • Healthcare professionals should assess cognitive ability when sharing information • Carers and relatives of patients who are cognitively impaired should be made aware of treatment regimens for the patients they care for and be encouraged to identify any need for clinical support • Management of HF should be seen as a shared responsibility between patient and healthcare professional. • Unless specifically excluded by the patient, carers and relatives should be involved in the management of the patient, particularly where the patient cannot look after him- or herself https://www.nice.org.uk/guidance/cg108	
CARER TASK/ISSUE	**STRATEGIES, GUIDELINES, KNOWLEDGE**	**SUPPORT/EDUCATIONAL PROGRAMMES/RESOURCES**
Chronic financial difficulties Carers often take over the household finances (Agren, Evangelista et al. 2010). Financial difficulties can	**NHS Choices** If a person cannot continue working as a result of HF, they may be able to claim disability and incapacity benefits. People over the age of 65 who are severely disabled may qualify for Attendance Allowance.	**Carers UK** DOWNLOADS available on: Attendance allowance Bedroom tax Benefit cap Bereavement Care act FAQ Care standards FAQ

challenge carers (Imes, Dougherty et al. 2011). Chronic financial worries are a major issue for HF patients and carers both during routine and hospital based treatment (Rocker and Cook 2013). In contrast to cancer patients, applications for state financial assistance and access to palliative care services show a very marked prevalence for cancer patients (Önac, Fraser et al. 2010).		Carers allowance Carers assessment http://www.carersuk.org/help-and-advice **Caring with Confidence** http://www.southnorfolkccg.nhs.uk/news/caring-confidence **Hospice UK** **Access to welfare or benefits advice.** http://www.hospiceuk.org/what-we-offer/care-support-programmes/family-and-carers **Marie Curie Cancer Care** Offer advice on money matters, including the blue badge scheme, Attendance Allowance and Disability Living Allowance, Carer’s Credit, Carer’s Allowance, Income Support, Housing Benefit and Council Tax mariecurie.org.uk/patientsandcarers **Carers direct** http://www.nhs.uk/CarersDirect/moneyandlegal/Pages/Moneyandlegalhome.aspx **BHF** **For advice on guidance to any benefit entitlement such as carer's allowance** https://www.bhf.org.uk/heart-health/living-with-a-heart-condition/caring-for-a-heart-patient
LIFESTYLE ISSUES		
CARER TASK/ ISSUE	**STRATEGIES, GUIDELINES, KNOWLEDGE**	**SUPPORT/EDUCATIONAL PROGRAMMES/RESOURCES**
Diet	**No added salt**	**The (COPE) study** (page 106)

All terms* and measures used by dieticians should be fully explained. One of the most prominent caregiving areas is taking care of the household, shopping (Agren, Evangelista et al. 2010). Caregivers of HF patients perform care tasks related to HF management, such as fluid restriction, managing sodium intake and weight monitoring (Hwang, Luttik et al. 2010).	One of the most important challenges in HF patients' self-care is compliance to a low-salt diet. Family members can play a specific role in encouraging patients' compliance to these dietary restrictions (Shahriari 2013). All patients need to * restrict salt intake to 2 to 3 g (0.5 tsp.) per day. Patients with unremitting fluid retention or advanced cardiac failure (ejection fraction less than 35%) require restriction to less than 2 g (e.g., approximately 0.25 tsp) of salt per day. Patients, especially those with renal dysfunction or hyponatremia, should restrict fluid intake to 1.5 to 2.0 L* per day (Gruszczynski, Schuster et al. 2010). *Saturated fatty acids should account for <10% of total energy intake, through replacement by * polyunsaturated fatty acids *Trans-unsaturated fatty acids: as little as possible, preferably no intake from * processed food, and <1% of total energy intake from *natural origin. • <5 g of salt per day • 30–45 g of * fibre per day, from *wholegrain products, fruits, and vegetables • 200 g of fruit per day (2–3 *servings) • 200 g of vegetables per day (2–3 servings) • Fish at least twice a week, one of which to be oily fish • Consumption of alcoholic beverages should be limited to two glasses per day (20 g*/day of alcohol) for men and one glass per day (10 g*/day of alcohol) for women Energy intake should be limited to the amount of energy needed to maintain (or obtain) a healthy weight, i.e., a body	**REACH II** **BHF Booklet "Living with HF"** (page 58) **DVD** **"So you have been diagnosed with HF"** See page 62 for appraisal

	mass index (BMI) <25 kg/m2.	
CARER TASK/ISSUE	**STRATEGIES, GUIDELINES, KNOWLEDGE**	**SUPPORT/EDUCATIONAL PROGRAMMES/RESOURCES**
Alcohol	**No more than 1 alcoholic drink per day** (Gruszczynski, Schuster et al. 2010) **NICE Guidelines on Chronic HF: Management of chronic HF in adults.** **Alcohol:** Patients with alcohol-related HF should abstain from drinking alcohol. Healthcare professionals should discuss alcohol consumption with the patient and tailor their advice appropriately to the clinical circumstances. https://www.nice.org.uk/guidance/cg108	**COPE study** (page 106) **Patient booklet** **Chronic HF** SIGN (SCOTTISH INTERCOLLEGIATE GUIDELINES) NHS quality improvement Scotland Page 60
CARER TASK/ISSUE	**STRATEGIES, GUIDELINES, KNOWLEDGE**	**SUPPORT/EDUCATIONAL PROGRAMMES/RESOURCES**
Exercise/ increasing activity Participation in regular physical activity and/or aerobic exercise training is associated with a decrease in CVD mortality (De Backer et al, 2012).	**Explain terms such as light, moderate, vigorous, aerobic.** Patients with previous acute myocardial infarction, coronary artery bypass graft (CABG), percutaneous coronary intervention (PCI), stable angina pectoris, or stable Chronic HF should undergo moderate-to-vigorous intensity aerobic exercise training ≥3 times a week and 30 min per session. Sedentary patients should be strongly encouraged to start light-intensity exercise programmes after adequate exercise-related risk stratification (De Backer et al, 2012). Following a stress test assessment. Patients can exercise	**REACH II** **Patient booklet** **Chronic HF** SIGN (SCOTTISH INTERCOLLEGIATE GUIDELINES) NHS quality improvement Scotland Page 60 **Effects of patient teaching, educational materials, and coaching using telephone on dyspnoea and physical functioning among**

	aerobically 3 to 5 times per week (30 to 40 minutes per session) (Gruszczynski, Schuster et al. 2010). Physiological responses to acute exercise may unmask patients with the worst clinical status and identify those at increased risk of poor outcomes (Alberto Jorge Alves,2010). **NICE Guidelines on Chronic HF: Management of chronic HF in adults in primary and secondary care.** **New 2010 guideline 3 Rehabilitation:** • Offer a supervised group exercise-based rehabilitation programme designed for patients with HF • Ensure the patient is stable and does not have a condition or device that would preclude an exercise-based rehabilitation programme • Include a psychological and educational component in the programme • The programme may be incorporated within an existing cardiac rehabilitation programme https://www.nice.org.uk/guidance/cg108	**persons with HF** (Wongpiriyayothar, 2011) **BHF Booklet "Living with HF"** (page 58) **DVD** **"So you have been diagnosed with HF"** See page 62 for appraisal

CARER TASK/ISSUE	STRATEGIES, GUIDELINES, KNOWLEDGE	SUPPORT/EDUCATIONAL PROGRAMMES/RESOURCES
Weight management Both overweight and obesity are associated with a risk of death in CVD, there being a positive linear association of BMI with all-cause mortality.	**Ensure households have weighing scales and can read/interpret the readings/dials** Take daily morning weight (nude and after voiding). Any weight gain of 2 lb (1 kg) in 1 to 2 days or, 5 lb (2 kg) in 1 week should be reported to GP (Gruszczynski, Schuster et al. 2010)	**COPE study** (page 106) **REACH II** **BHF Booklet "Living with HF"** (page 58) **DVD** **"So you have been diagnosed with HF"** See page 62 for appraisal

All-cause mortality is lowest with a BMI of 20–25 kg/m2. Further weight reduction, however, cannot be considered protective against CVD (De Backer et al, 2012).		
CARER TASK, ISSUE	**STRATEGIES, GUIDELINES, KNOWLEDGE**	**SUPPORT/EDUC PROGRAMMES/RESOURCES**
Smoking cessation **Changing smoking behaviour is a vital to improving CVD health** (De Backer et al 2012) (Gruszczynski, Schuster et al. 2010).	**Support groups** **NICE Guidelines on Chronic HF: Management of chronic HF in adults in primary and secondary care** **1.2.1 Lifestyle Smoking:** • Patients should be strongly advised not to smoke • Referral to smoking cessation services should be considered. https://www.nice.org.uk/guidance/cg108	**DVD** **"So you have been diagnosed with HF"** See page 62 for appraisal
CARER TASK/ISSUE	**STRATEGIES, GUIDELINES, KNOWLEDGE**	**SUPPORT/EDUCATIONAL PROGRAMMES/RESOURCES**
Fatigue	Check with HCPs. Fatigue can sometimes be improved with adjustment of medication or device therapy (Connolly, Beattie et al. 2014).	**Patient booklet** **Chronic HF** SIGN (SCOTTISH INTERCOLLEGIATE GUIDELINES) NHS quality improvement Scotland (SIGN) Page 60 **DVD** **"So you have been diagnosed with HF"** See page 62 for appraisal

Preventive measures Elevated blood pressure (BP) is a major risk factor for CHD, HF, cerebrovascular disease, peripheral artery disease (PAD), renal failure, and atrial fibrillation (De Backer et al 2012).	Recommendations on: • Blood Pressure • Lifestyle measures such • Weight control • Increased physical activity • Moderating alcohol • Sodium restriction • Increased consumption of fruits, vegetables, and low-fat dairy products in all patients with hypertension and in individuals with high normal BP (De Backer et al, 2012) **Influenza and pneumococcal vaccination** **(**Gruszczynski, Schuster et al. 2010) **Chronic HF: Management of chronic HF in adults in primary and secondary care. NICE Guidelines on:** **Vaccination** 1.2.1.5 Patients with HF should be offered an annual vaccination against influenza.**[2003]** 1.2.1.6 Patients with HF should be offered vaccination against pneumococcal disease (only required once). **[2003]** https://www.nice.org.uk/guidance/cg108.	**COPE study** (page 106) **Patient booklet** **Chronic HF** SIGN (SCOTTISH INTERCOLLEGIATE GUIDELINES) NHS quality improvement Scotland Page 60 **BHF Booklet "Living with HF"** (page 58) **DVD** **"So you have been diagnosed with HF"** See page 62 for appraisal (Boyde, Song et al. 2013)
CLINICAL ISSUES		
CARER TASK/ISSUE	**STRATEGIES, GUIDELINES, KNOWLEDGE**	**SUPPORT/EDUCATIONAL PROGRAMMES/RESOURCES**
Complex medication regimens There are gaps in the evidence for symptom	**Caregivers of HF patients perform medication management care tasks related to HF** (Hwang, Luttik et al. 2010). **Caregivers have expressed a need for receiving**	**COPE study** (page 106) **Patient booklet** **Chronic HF** SIGN (SCOTTISH INTERCOLLEGIATE GUIDELINES)

control, especially for symptoms other than pain or dyspnoea, but recommendations are becoming increasingly evidence based (Gadoud, Jenkins et al. 2013).	**expert symptom management, and to be recognised as vital members of the health care team** (Rocker and Cook 2013).	NHS quality improvement Scotland Page 60 **BHF Booklet "Living with HF"** (page 58) **DVD** **"So you have been diagnosed with HF"** See page 62 for appraisal
CARER TASK/ ISSUE	**STRATEGIES, GUIDELINES, KNOWLEDGE**	**SUPPORT/EDUC PROGRAMMES/RESOURCES**
Patient anxiety and depression Patients with an HF diagnosis tend to have more depressive symptoms than the healthy population, but also in comparison to patients with other chronic conditions (de Vries et al, 2011). The COINCIDE trial offers a template for how integrated collaborative care can be potentially implemented within the context of routine chronic disease management with only minimal changes to the organisation of primary care (Coventry et al, 2012).	Collaborative care incorporating brief low intensity psychological therapy delivered in partnership with practice nurses in primary care can reduce depression and improve self-management of chronic disease in people with mental and physical multimorbidity (Coventry, et al 2012). **In the case of clinically significant symptoms of depression, anxiety, and hostility,** psychotherapy, medication, or collaborative care should be considered. This approach can reduce mood symptoms and enhance health-related quality of life, although evidence for a definite beneficial effect on cardiac endpoints is inconclusive (De Backer et al, 2012). Patients struggle to cope physically and psychologically with their reduced physical capabilities and fear being a burden to their carers (Ivany, 2015). **NICE Guidelines on Chronic HF: Management of Chronic HF in adults in primary and secondary care**:	**COPE study** (page 106) **REACH II** **Patient booklet** **Chronic HF** SIGN (SCOTTISH INTERCOLLEGIATE GUIDELINES) NHS quality improvement Scotland Page 60 **Macmillan. Hello and how are You?A guide for carers by carers** Sections for carers and patients on: • Depression • Anxiety • Anger • Frustration • Fear http://be.macmillan.org.uk/Downloads/MAC5767HelloAndHowAreYou.pdf **BHF Booklet "Living with HF"** (page 58) **"So you have been diagnosed with HF"**

The most onerous caregiving tasks are those dealing with patients' behavioural problems (Agren, Evangelista et al. 2010).	**1.5.8 Anxiety and depression (all 2003)** • The diagnosis of depression should be considered in all patients with HF • Where depression is likely to have been precipitated by HF symptoms then reassessment of psychological status should be undertaken once the physical condition has stabilised following treatment for HF • If the symptoms have improved no further specific treatment for depression is required • Where it is apparent that depression is co-existing with HF, then the patient should be treated for depression in line with: 'Depression: the treatment and management of depression in adults' (NICE clinical guideline 90) and 'Depression in adults with a chronic physical health problem: treatment and management' (NICE clinical guideline 91). • For patients with HF, the potential risks and benefits of drug therapies for depression should be considered carefully. • Patients with HF should consult a healthcare professional before using over-the-counter therapies for depression such as St John's wort (*Hypericum perforatum*) • Healthcare professionals should be aware of the potential interaction with prescribed medication, and always ask about self-medication, including the use of herbal products https://www.nice.org.uk/guidance/cg108.	**DVD** See page 62for appraisal **“Coping with low mood and depression for people with heart disease and/or diabetes”** Patient Manual COINCIE materials (page 50) COINCIDE Workbook COINCIDE PWP Manual

CARER TASK/ISSUE	STRATEGIES, GUIDELINES, KNOWLEDGE	SUPPORT/EDUCATIONAL PROGRAMMES/RESOURCES
Pain (angina or other) oedema, constipation, muscular fatigue and dyspnoea	There are gaps in the evidence for symptom control, especially for symptoms other than pain or dyspnoea. However, recommendations are becoming increasingly evidence based (Gure, Blaum et al. 2012, Gadoud, Jenkins et al. 2013).	**COPE STUDY** (page 106) **Patient booklet** **Chronic HF** SIGN (SCOTTISH INTERCOLLEGIATE GUIDELINES) NHS quality improvement Scotland Page 60 **DVD** **"So you have been diagnosed with HF"** See page 62 for appraisal

CARER TASK/ ISSUE	STRATEGIES, GUIDELINES, KNOWLEDGE	SUPPORT/EDUC PROGRAMMES/RESOURCES
Patient cognitive impairment Cognitive impairment is common in older adults with HF and is independently associated with risk of dementia. A cognitive assessment should be routinely incorporated into HF-focused models of care (Gure, Blaum et al. 2012).	Carers should be aware that there may be cognitive decline with HF (particularly those with systolic HF). This can result in an increased risk for several negative health outcomes including general cognitive impairment, frailty and depression. This puts them at risk for poor disease management and functional dependence. Cognitive impairment can affect the individual's ability to manage their health themselves, especially a complex chronic illness. Specific cognitive deficits, memory impairment and executive function deficits such as problems with regulation of one's behaviour may negatively influence self-management of an illness, such as reduced medication adherence. Other executive function deficits such as planning	**COPE study** (page 106) **REACH II** **The National Council for Palliative Care has produced publications about HF and the Mental Capacity Act.** www.ncpc.org.uk/publications

	difficulties and reduced cognitive flexibility may result in missed appointments and inability to make diet changes (Eggermont, de Boer et al. 2012)	
CARER TASK/ISSUE	**STRATEGIES, GUIDELINES, KNOWLEDGE**	**SUPPORT/EDUCATIONAL PROGRAMMES/RESOURCES**
Patient self-monitoring	**NICE Guidelines on Chronic HF: Management of Chronic HF in adults in primary and secondary care:** **1.4.1 Clinical review** All patients with Chronic HF require monitoring. Patients who wish to be involved in monitoring of their condition should be provided with sufficient education and support from their healthcare professional to do this, with clear guidelines as to what to do in the event of deterioration. **[2003]** https://www.nice.org.uk/guidance/cg108.	**BHF Booklet "Living with HF"** (page 58) **DVD** **"So you have been diagnosed with HF"** See page 62 for appraisal
CARER TASK/ ISSUE	**STRATEGIES, GUIDELINES, KNOWLEDGE**	**SUPPORT/EDUCATIONAL PROGRAMMES/RESOURCES**
Anaemia and iron deficiency The 2009 Focused Update to the American College of Cardiology/ American Heart Association HF guidelines[13] statement indicates that the severity of anaemia may contribute	Anaemia is frequent in patients with HF Factors associated with anaemia in chronic HF include: • older age • diabetes • chronic kidney disease (CKD) • more advanced HF (higher New York Heart Association [NYHA] class • more recent HF hospitalisations • more signs of HF	**COPE study** (page 106)

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[13] *Hunt SA, Abraham WT, Chin MH, et al.: 2009 focused update incorporated into the ACC/AHA 2005 Guidelines for the Diagnosis and Management of HF in Adults: a report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines: developed in collaboration with the International Society for Heart and Lung Transplantation. Circulation 2009, 119:e391–479.*

to the increasing severity of HF. Clinically, it is unclear whether anaemia is the cause of decreased survival or a result of more severe disease (O'Meara and de Denus 2010). A decline in Hb over time is also associated with mortality and morbidity	• lower exercise tolerance and quality of life. • in patients with HF, anaemia and CKD are both independent predictors of mortality and hospitalisations • even mild anaemia is associated with worsening of symptoms, increased NYHA class, as well as impairment in functional capacity and quality of life (O'Meara and de Denus 2010)	

CARER TASK/ ISSUE	**STRATEGIES, GUIDELINES, KNOWLEDGE**	**SUPPORT/EDUCATIONAL PROGRAMMES/RESOURCES**
Breathlessness Breathlessness is one of the most important symptoms of patients with Chronic HF. Breathlessness impacts greatly on patients and family caregivers. It results in avoidance of exertion and deterioration of functional status. Functional impairment then leads to dependence on carers and patients' social limitations. The consequences of	NICE GUIDELINES FOR REVIEW ON • breathlessness • anticipatory prescribing Additional reference: (Ekström, et al, 2015) The management of chronic breathlessness in patients with advanced and terminal illness *BMJ* 2015;349:g7617 doi: 10.1136/bmj.g7617	**Patient booklet** **Chronic HF** SIGN (SCOTTISH INTERCOLLEGIATE GUIDELINES) NHS quality improvement Scotland Page 60 **DVD** **"So you have been diagnosed with HF"** See page 62 for appraisal **BHF Booklet "Living with HF"** (page 58)

living with breathlessness arise in all aspects of daily life of patients, their family caregivers and their social environment (Janssen, et al, 2015a).		
CARER TASK/ ISSUE	**STRATEGIES, GUIDELINES, KNOWLEDGE**	**SUPPORT/EDUCATIONAL PROGRAMMES/RESOURCES**
Quality of life Limited mobility, restricted social life, poor quality of life, patients struggled to cope physically and psychologically with their reduced physical abilities (Ivany, Elena)	**Of all the general medical conditions HF has the greatest impact on quality of life** (Connolly, Beattie et al. 2014)	**COPE study** (page 106) **Patient booklet** **Chronic HF** SIGN (SCOTTISH INTERCOLLEGIATE GUIDELINES) NHS quality improvement Scotland Page 60 **BHF Booklet "Living with HF" (**page 58)

PATIENT AND CARER EDUCATION AND SUPPORT IS KEY TO HF MANAGEMENT.

Section 10. Good practice

10.1 Greater Manchester HF Investigation Tool (GM HFIT)

This project aims to increase awareness of HF and improve GPs knowledge and skills in this condition in order to manage them more effectively. To date this has been successful in terms of GPs responses to improving their care for HF patients. Seven additional practices have now been recruited. A community HF nurse has been recruited to work with nurse practitioners and HF specialist nurses in order to support work on validating HF registers and helping to identify HF patients.

http://clahrc-gm.nihr.ac.uk/2012/10/more-practices-in-greater-manchester-set-to-improve-care-for-heart-failure-patients/#sthash.lVjj7iDl.dpuf

10.2 Building the House of Care - How health economies in Leeds and Somerset are implementing a coordinated approach for people with long-term conditions.

This is a coordinated approach to personalised care and support planning. This paper contains case studies of evolving practice in Leeds and Somerset, both of whom are dedicated to a new way of working to support people with LTCs. There is growing recognition that new ways of working are needed to meet increasing health care demand and cost pressures, while continuing to provide a high quality service that meets people's needs. Although implementing a new model in local health economies in the current climate is challenging, Somerset and Leeds are starting to find ways to embed the approach into their local systems. So far they have progressed well, gaining commitment at all levels from multiple partners and sectors, adapting the original model to varying degrees. Leeds has maintained the original House of Care model, whereas in many areas of Somerset non-clinical staff are carrying out the care and support planning consultation, a change made in response to GPs' and other health care professionals' time pressures, as well as locally available resources. It is not yet known just how flexible the model is to adaptation.

Both case studies present three broad system approaches to spreading the House of Care across the local health economy: financial incentive, nudge and encouragement. In Leeds South and East CCG ('financial incentive') practices have signed up to the House of Care relatively quickly; somewhat slower in Leeds North CCG and Leeds West CCG ('nudge'); and in Somerset various approaches to the House of Care are emerging ('encouragement').

This paper specifically explores how to embed a new model into a pre-existing system, to what extent can and should the model be adapted to the local context, and what is the best approach to achieving spread. The case studies provide good examples of how two localities are normalising a new way of working in health and social care through an enabling and coordinated approach. The House of Care is one way of energising local stakeholders to think and work differently; other health economies may also be inspired to transform their own systems.

Précised from (Taylor, 2015).

http://personcentredcare.health.org.uk/sites/default/files/resources/buildingthehouseofcare_0.pdf

PART 3. EOL CARE AND ADVANCED HF

11.1 Introduction

End Stage HF (ESHF) is usually associated with a risk of sudden death being dramatically increased (Princess Royal Trust (2010) and for a considerable proportion of patients dying of cardiovascular disease their ultimate death was perceived as sudden and/or unexpected by relatives (voices survey). Responding to the individual needs of these patients, and the needs of their carer is an enormous challenge for both health and social care and novel approaches to EoL planning are still needed in severe HF (Imes, Dougherty et al. 2011).

The palliative care needs of HF patients were first recognised when UK National guidelines acknowledged considerable unmet need for palliative care in HF, planning for the future and EoL Care (EoLC). Although community-based HF nurses have been in place since 2003: their focus is primarily on optimising medical management and admission reduction. The national audit of people admitted to hospital with HF highlights the importance of specialist cardiology teams in managing acute episodes. Long-term care, however, is largely undertaken in primary care by informal carers. However, HF care involves complex technical issues and drug regimes, and often HCPs are the main decision makers (Barclay, Momen et al. 2011).

Despite a growing recognition of the requirement to provide supportive and palliative care for HF patients (Gadoud, Jenkins et al. 2013), the recent National HF Audit[14] highlighted continuing significant unmet needs with only 6% of those dying with HF being referred to palliative care (Jaenicke, et al, 2015). Palliative care (PC) could contribute to HF EoL Care especially in the terminal phases. Barriers to referal include difficult prognostication due to the unpredictable disease trajectory and inadequate initiation of conversations about EoL Care (Gadoud, Jenkins et al. 2013). Evidence suggests that EoL Care in HF is poor, characterised by high levels of symptoms, inadequate support and poor quality of life (QoL) for both patients and carers so it is important to explore how PC programmes should be integrated into the care plan for HF patients. Needs of carers throughout the EoL process should be explored in order to inform PC programmes for HF patients (Breslin, Fitzsimons et al. 2014).

It is important to explore how PC programmes should be integrated into the care plan for HF patients (Breslin, Fitzsimons et al. 2014) given that there is a clear role for specialist palliative care in the terminal phase of HF (Gadoud, Jenkins et al. 2013). This could be provided on a

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[14] *The NHS Information Centre for Health and Social Care (2009). National HF Audit. Third report for the audit period between April 2008 and March 2009. (http://www.hscic.gov.uk/article/2021/WebsiteSearch?q=Hospital%2BEpisode%2BStatistics&infotype=13361&sort=Title&size=10&page=7&area=both)*

consultancy basis in the community or in hospices or hospitals. Specialist palliative care and cardiologists have collaborated successfully in the past in this endeavour (Johnson amd Houghton, 2006).

Table 5 Key principles of palliative care

(Ward, Donnelly et al. 2014).	
It provides symptom management	Providing relief from physical aspects of life limiting illness, including pain, shortness of breath, nausea, fatigue and emotional, spiritual or psychosocial needs. To manage symptoms, many medications may be given subcutaneously because the patient has difficulty or may no longer be able to swallow because of the disease process and absorption via the oral route may not be as effective.
Accepts that dying is a natural process	Coming to terms with death and aspects that are important to the individuals concerned are examined. This could include whether a person wants to be at home, stop or continue with active treatment.
Encompasses both psychological and spiritual aspects of an individual	The treatment of 'total suffering' or 'total pain' is important in palliative care. That is not just dealing with a patient's physical suffering but also their emotional, psychological and spiritual suffering. In practice this may be prescribing pain killers and at the same time offering on-going support from perhaps, a social worker, counsellor or chaplain working with the patient and possibly their family. This support can address other factors causing distress in order to improve quality of life for all. It also helps in the provision of support systems for family of patients to help them cope and to give respite whilst caring for the patient.
Is multi-disciplinary	A whole team are involved in a palliative care approach in caring for a patient and their family including doctors, nurses, social workers, counsellors, chaplaincy, pharmacists and a variety of other allied health professionals and volunteers.

11.2 Main issues in advanced HF

11.2.1 EoL conversations

Whilst guidelines recognise that there needs to be more open communication between the public and the NHS about EoL issues, it also recognised that some patients and some HCPs may not wish to hold such discussions. Discussing EoL issues with HF patients and families is a difficult conversation to have, not only because of the uncertainty (Barclay, Momen et al. 2011) (Ivany, 2015), because the term ‘HF’ is frightening and the condition difficult to explain to people who are not medically trained and cannot grasp the nature and gravity of their condition (Barclay, Momen et al. 2011). These conversations are further inhibited because cardiac-specific barriers exist to identifying and supplying palliation needs for HF patients (Ivany, 2015).

A recent systematic review focussed exclusively on studies of patients with HF. This examined the literature concerning conversations about EoL care between patients with HF and HCPs in terms of:

- the prevalence of conversations
- patients’ and practitioners’ preferences for their timing and content
- the facilitators and blockers to conversations

The systematic review concluded that current models of EoL care do not meet the needs of HF patients. Conversations with patients and carers mostly focus largely on disease management with EoL care rarely discussed. Some patients would welcome such conversations, others do not realise the gravity of their condition and/or do not wish to discuss EoL issues. Clinicians - fearing they may cause premature alarm and destroying hope - wait for cues from patients before raising EoL care issues. Given that predicting the time of a patient’s death is almost impossible, HCPs find it difficult to initiate EoL care conversations. Patients may have been close to death on several occasions. Consequently, these conversations are rare (Barclay, Momen et al. 2011). Judging when and how to discuss changes in treatment emphasis, goals of care and advance care planning with a patient and their carer therefore, is difficult and often left too late. HF specialists have only recently begun to engage in this practice (Jaenicke, et al, 2009), with few being currently trained in conducting such difficult conversations (Connolly, Beattie et al. 2014).

In many conditions, many ‘EoL conversations’ are largely limited to advanced directive paperwork and choices about resuscitation rather than communication about goals and future care options. There is often ambiguity as to whether EoLC conversations have taken place at all, and discrepancies are often reported in perceptions of the amount of information exchanged between patients, carers and HCPs (Barclay, Momen et al. 2011).

Connolly et al, cite a list of criteria for poor prognosis in HF patients which could be conveyed to patients and carers and thus act as catalysts for discussion with families about death and instigating EoL Care:

- advanced age
- with refractory symptoms despite optimal therapy
- who have had at least three hospital admissions with decompensation in less than six months
- who are dependent for more than three activities of daily living
- with cardiac cachexia
- with resistant hyponatraemia
- with serum albumen of less than 25g/l
- who experience multiple shocks from their device
- with a comorbidity conferring a poor prognosis, such as terminal cancer (Connolly, Beattie et al. 2014)

Imes, et al, 2011, found that very few patient/partner dyads spent any time discussing the future or making EoL decisions. They had ideas about a good death, but few had advance directives in place to ensure that this took place. Despite suggestions in published guidelines, HCPs are not proactive about providing EoL information or encouraging discussions about these issues. Also, people do report that receiving life expectancy information from healthcare providers regarding the long-term survival of patients is not useful and can frighten or confuse patients. Post death, carers identified four common themes occurred about the process:

(1) the lack of availability of treatment options for certain patients, prompting patients and caregivers to consider broader EoL issues
(2) changes in preferences at the very end of an illness
(3) variability in patients' and caregivers' desire for and readiness to hear information about a patient's illness
(4) difficulties with patient-caregiver communication.

Overall, partners focused on four aspects of the patient's experience, i) symptoms, ii) disease course and duration, iii) dying, and iv) the future, the latter being the most difficult to manage and deal with emotionally. Family interventions prioritising these areas in the future may enhance adaptation by partners who are caring for a patient with advanced HF at home (Imes, Dougherty et al. 2011).

Conducting a local needs assessment could also indicate to families that the patient is at the EoL and initiate these conversations[15].

Given the uncertain trajectory of a HF patient, there may not be time to instigate EoL conversations if the patient dies soon after diagnosis, suddenly during a 'responding to treatment' phase, or dies during a period of clinical instability. The times this could happen are if a patient has spent weeks, months or years with poor response to treatment.

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[15] *For an example of a protocol for this please see:* http://www.nhsiq.nhs.uk/media/2574509/end-of-life-care-in-heart-failure-framework-for-implementation.pdf

The communication challenges for EoL care in HF are considerable, HCPs not being comfortable with breaking bad news. National guidelines for supportive and palliative care for advanced HF in 2004 highlighted the need for advanced communication skills training for clinicians (Barclay, Momen et al. 2011).

HCPs tend to focus on current aspects of medical management rather than the future and this may hinder discussions around EoL care because they fear alarming patients and destroying their hope. Although HCPs believe that HF patients should know of their prognosis, when to give this information is difficult. The risk of sudden death has to be balanced between frightening patients whilst not underplaying their condition. In addition, some HF patients may not wish to know they are dying, and HCPs are unsure how to recognise signs that a patient may wish to initiate a conversation about death. Other HCPs view it as inappropriate for them to initiate EoLC discussions, and use their own judgement about what information patients may or may not want to hear, and when in practice this commonly means waiting for patients to initiate a conversation, although they recognise that some, especially older people, may be reluctant to raise such issues with their doctors. Rather than a one-off conversation, this is seen as a process over time, based on an established and trusting relationship between doctor and patient (Barclay, Momen et al. 2011).

"The ethical balance between beneficence and non-maleficence can be hard to find". A 'good death' in HF is when a patient understands what is happening and they are able to plan ahead and talk about their wishes. A 'bad death' is unexpected, where HCPs have not been open about what is happening, and the patient has no insight and is therefore unprepared (Barclay, Momen et al. 2011)(e60).

HF patients need clinicians to be sensitive to their individual wishes for EoL conversations, which change as events and time unfold. HCPs need to recognise cues that HF patients would like to talk further about their prognosis. Those who view open awareness as the best way to prepare for the EoL need to live with the internal tensions created when patients are reluctant to discuss this. A dual approach of continuing active treatment while acknowledging the possibility of death could be a way forward. 'Hoping for the best but preparing for the worst' appears to be a good balance and a way into these conversations (Barclay, Momen et al. 2011).

Although most HCPs believe patients should be told the truth, many withhold information or avoid EoL conversations. Prognostic uncertainty, time pressures, lack of communication skills training, feeling of medical failure, uncertainty about timing and content, and fear of upsetting patients have all been suggested as contributing to this reluctance. Although past guidelines have recommended frank conversation, (in the US discussions of advanced directives are legally mandated for all hospitalised patients), in practice such conversations are rare in the UK for patients with a wide range of life-limiting illnesses (Barclay, Momen et al. 2011). Health Providers should be encouraged to develop advance care planning, and it is important that such decisions are fully informed, regularly reviewed, properly recorded and accessible to providers connolly across all care sectors (Connolly, Beattie et al. 2014)(Johnson and Houghton, 2006: Barclay, Momen et al, 2011).

10.2.2 Deactivation of defibrillator issues

An implantable cardioverter defibrillator (ICD) is a small device that is placed in the chest or abdomen and links to the heart. The device uses electrical pulses or shocks to help control life-threatening arrhythmias. Patients with an ICD often suffer from progressive conditions in which case a stage may be reached when it is no longer medically appropriate for the device to be used. At this time, and following discussion with the patient, their family, carers and medical team, a decision can be made to turn off or 'deactivate' the device. Deactivation of the shock mode of an ICD does not deactivate the pacemaker function and in itself does not end a patient's life. It does, however, allow for a natural death without the risk of unpleasant and unnecessary shocks. Where appropriate, deactivation should be discussed in advance, to enable the elective withdrawal of device therapy. This in turn will enable deactivation to be a supported process to the benefit of patients and carers – ensuring that device therapies will not be delivered and avoiding unnecessary distress to the patient or relatives.

Discussion about de-activating the ICD should take place as early as appropriate in the patient's management to enable pro-active care management and to avoid unnecessary distress – this may include a discussion about the prospect of future withdrawal prior to implant. Reactivation of the ICD may be considered if the patient recovers sufficiently from a worsening of their condition. Professional support is important in helping patients and carers to cope with all of the implications of ICD therapy. (http://www.gmccsn.nhs.uk/files/8113/6983/8277/ICD_Deactivation_PolicyFinal_V1.0.pdf)

Few patients and their partners are aware of the unique EoL issues associated with deactivating the ICD near or at the time of death. HCPs communicate about these issues at the time of ICD implantation, and again, when a patient's condition worsens (Imes, et al, 2011). Handling of implanted devices is important after death requiring deactivation of defibrillator function if applicable, and devices need to be explanted prior to cremation (Connolly, et al, 2014).

European and International guidelines recommend HCPs discuss deactivation with patients prior to ICD implantation. However, there is still enough doubt about the appropriate therapeutic management of an ICD at the EoL for these conversations to be difficult. A retrospective case of current practice showed that there was no documented evidence that a cohort of patients were informed about deactivation, prior to ICD implantation. They were not adequately informed regarding device deactivation prior to, neither implantation, nor when their health deteriorated. The experience of a shock potentially affects professional decision making regarding device deactivation and it is preferable to deactivate ICDs near the EoL to avoid increases in device shock. It remains crucial to disentangle whether the increased susceptibility of being shocked at the EoL outweighs the therapeutic benefit of an ICD.

Many HCPs are uncomfortable and uncertain about initiation of a discussion related to deactivation of the ICD due to the uncertain prognosis in HF, because they lack experience with the 'intrinsic nature of it and discussion about ICD deactivation is not often seen as not integral to routine practice. The use of deactivation protocols is diverse across countries and in order to enhance compliance of practice to international expert guidelines, clinical factors which facilitate or inhibit decision to discuss ICD deactivation need to be identified.

For patients' benefit, HCPs need to be aware of each patient's unique information needs and preferences. However, all these demands serve to inhibit such discussions and disallow patients and carers to share in this particular decision and stifles shared decision-making. Patients have been documented as considering that pre-implantation, followed by EoL are the best times to discuss ICD deactivation - although this rarely happens. As their condition progresses many patients are reluctant to deactivate their device for fear of losing 'minimal hope for some eventual curative option'. The decision to deactivate is complex and further research and expert guidance is needed to improve education and practice (Hill et al, 2014, 2015).

Also see. Deactivating the shock function of an implantable cardioverter defibrillator towards the end of life: A guide to when it may be best for you to have the shock function of your ICD turned off, for patients and carers.

https://www.bhf.org.uk/~/media/files/publications/living-with-a-heart-condition/cieds_leaflet.pdf

10.2.3 Breathlessness in advanced HF

Worldwide, 50% of the 23 million people with HF suffer from breathlessness which increases as the disease progresses, symptoms frighten patients and families, and often results in emergency hospital admission (Higginson, 2014). Chronic breathlessness, often defined as breathlessness for more than 4-8 weeks, is common in Chronic HF and often more severe and longer lasting than in cancer patients (Ekstrom, Abernethy et al. 2015). Being a persistent, frequent core symptom for patients with HF, this can be perceived as contributing to the negative effects of other symptoms (Gysels and Higginson 2011). The psychological and social consequences of breathlessness result in putting a strain on family carers. Multidimensional treatment programmes are desirable in order to support patients with advanced disease and their family caregivers (Janssen, 2015 a/b). A major intervention and resources for breathlessness (the BIS) is below (page 108) with evidence to support the adoption of a Breathlessness Support Service.

10.2.4 Caregiver depression

HF caregivers are at risk for higher levels of depression. Identifying and treating them is important to improve their QOL. It is important to identify and treat caregivers who screen positive for depression. A suggested screening tool is the PHQ-9 (Nauser, et al, 2011).

10.2.5 General carer needs

Little is known about the HF caregiver experience and what constitutes the best care for them. (Rocker and Cook 2013). To date, studies have focused on the experiences of bereaved caregivers or their satisfaction with EoL care with no comprehensive evaluation of their needs throughout and beyond the EoL process (Breslin, Fitzsimons et al. 2014). They are important partners in care and seriously affected by advanced HF. Our knowledge about the longitudinal effects on them is also scarce (Stromberg 2013). See table 6 below, Evidence for carer needs and requirements.

Table 6 Evidence for carer needs and requirements

Caregivers have expressed specific desires related to HF care which include:

- that there is an early integration of palliative care into current care (Buck, Zambroski, et al. 2013) (Rocker and Cook 2013)
- that they would receive expert symptom management
- that they would be recognised as vital members of the health care team (Rocker and Cook 2013)

HF patient and carer needs include:

- general palliative care
- specialist palliative care
- EoL Care
- social/financial support
- spiritual care
- family/bereavement care
- psychological support
- symptom control (Connolly, Beattie et al. 2014)

- psychosocial support to maintain a sense of normality
- support with daily living
- support with navigating the healthcare system
- carers' needs begin at the point of a patient's diagnosis and continue until bereavement and should be prioritised throughout the disease trajectory
- support should be holistic and include HF and palliative care specialties (Doherty, Fitzsimons et al. 2015).

For advanced HF patients, a review identified the following core caregiver needs:

- support
- information
- time and communication with professionals
- to feel valued
- self-care (Breslin, Fitzsimons et al. 2014)

HF patients and their caregivers lack:

- sufficient palliative care
- communication on prognosis and EoL Care (Stromberg 2013)

10.2.6 LGBT Carer needs

"Caring Together" - The document "Caring Together". The Carers Strategy for Scotland has addressed LGBT and BAME carers (and indeed disabled carers) setting out key actions to improve support to these groups of carers over the next five years. These are as follows:

- The Equality Act 2010 is intended to protect the rights of individuals and advance equality of opportunity for all; to update, simplify and strengthen the previous legislation; and to deliver a simple, modern and accessible framework of discrimination law which protects individuals from unfair treatment and promotes a fair and more equal society
- Ensuring equalities in race or ethnicity, disability, gender or sexual orientation, age or religion means ensuring opportunity for all carers to access suitable resources and support
- Support needs to be delivered in a sensitive way
- Health and social care professionals need to be sensitive to different forms of caring relationships

Culturally competent services should be delivered and all those involved in EoL Care should be culturally competent **for all minority groups** (Government 2010).

In the UK, accurate numbers of people who identify themselves as lesbian, gay, bisexual or transsexual (LGBT) are hard to establish. Official figures vary between 750,000 and 3.6 million. In 2009, the number of people who had sought gender reassignment treatment was estimated at 12,500, with the expectation that this figure will grow as more transsexual people feel able to seek increasingly available support.

LGBT people are at risk of not receiving high-quality EoL Care services, with many facing problems in terms of being treated with dignity and respect. Having a LGBT identity can sometimes directly impact on the experience of EoL Care. The National EoL Care Programme has been developed following consultation with stakeholders at a series of discussion groups held around the country. The document offers guidance and advice for those working with LGBT people, and for LGBT people themselves, whether giving or receiving EoL Care. The guide aims to:

- encourage LGBT people to be confident in being open about their relationships and needs
- guide organisations and people within them to have an LGBT-friendly culture
- highlight constructive key messages for everyone to act upon

Following the six steps of the EoL Care Pathway, each section in the document below identifies issues to consider and links them to practitioner and staff roles. Case studies are used to highlight good practice and key recommendations for future practice are included.

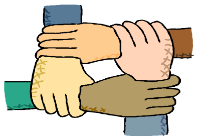
The National EoL Care Programme (The route to success in EoL Care – achieving quality for lesbian, gay, bisexual and transgender people.
www.nhsiq.nhs.uk
www.endoflifecare.nhs.uk/search-resources/resources-search/publications/the-route-to-success-in-end-of-life-care-%E2%80%93-achieving-quality-for-lesbian-gay-bisexual-and-transsexual-people.aspx

Age UK also offers support for older Lesbian, Gay, Bisexual and Transsexual people
http://www.ageuk.org.uk/health-wellbeing/relationships-and-family/lgbt-information-and-advice/lesbian-gay-bisxual-or-transgender-in-later-life/

In relation to BAME carers, carer training might be delivered to BAME female carers in their own right. In relation to gender issues, professionals have to recognise that daughters in certain cultures may not wish to carry out personal care for their fathers.

10.3 HF and EoL Specific programme and resources

Table 7 HF EoL specific programmes and resources

FLAG	PROGRAMMES & APPRAISAL
"CARE PLUS"  ★ ★ This project gained National recognition for Tower Hamlets partners: • Noted by the National Audit Office VFM report–EoL Care (Nov 2008)	**"Care-Plus"**[16] Testing of an integrated Support Package providing enhanced services for carers (aged 18+) caring for patients with End Stage HF (ESHF), meaning NYHA stages 3 & 4[17] in Tower Hamlets. A 3 year research project funded by the Kings Fund in a cross-sector partnership between: Carers Centre Tower Hamlets, Lambeth Adults Health & Wellbeing Tower Hamlets PCT. This project aimed to promote Dignity in Dying and was aimed specifically at HF and COPD patients in the last year of their life. The aim of the project is to provide a single point of contact for care coordination and routes in to support services including fast-tracking to appropriate services, tailored coordination of care, access to a care coordinator for people with ESHF and their carers. Its aims were: • An early identification of patients diagnosed with ESHF in Tower Hamlets • Improved access to health & social care provision for patient, carer & family by taking on a co-ordinating role • Achieve a better EoL experience for patient, carer and family • Foster a greater awareness amongst professionals of the range of services available to patients and their Carers • Minimise the possibility of breakdown of the Caring role resulting in emergency hospital/respite admissions • To increase patients ability to choose and implement their preferred place of care

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[16] *The name "Care-Plus" has been protected for the use of this organisation only*

[17] *Functional classification of HF as determined by the New York Heart Association Functional Classification (NYHA). Criteria Committee of the New York Heart Association. Nomenclature and criteria for diagnosis of diseases of the heart and great vessels. 9th ed. Boston: Little, Brown & Co; 1994. p. 253-6.The I-IV score documents the severity of symptoms, and can be used to assess a patient's responsiveness to treatment.*

• Noted on The DoH national EoL Care website- as an example of good practice • Identified as good practice by the Kings Fund • Noted in the “Carers Trust” excellence section Contact Lynn Middleton at; PRTC Carers Centre Tower Hamlets 21 Brayford Square London E1 0SG Tel: 020 7790 1765 Fax: 020 7790 7073 www.carerscentretowerhamlets.org.uk Email: enquiries@carerscentretowerhamlets.org.uk	• A significant reduction in deaths occurring in hospitals Services provided by the Care-Plus project included counselling, social Advocacy activities that improve quality of life and support with financial issues, for example benefit applications and maximising income. The project co-ordinator was also able to make applications for funding from charitable trusts when needs fell outside the remit of social care funding. A referral protocol specifically for EoL Care packages has also been developed with St Joseph’s hospice, enabling the co-ordinator to make direct referrals of patient and or carers into their services. The evidenced outcomes were successful fast tracking to appropriate services, tailored coordination of care and an approach that works for the individuals but also for the organisations providing the goods and services. The Carers centre were able to be more flexible and could meet carer needs without the same bureaucratic constraints faced by public service providers, for example, providing portable nebulisers in order to improve mobilisation and quality for patient and carers and offer a short term wheelchair loan facility for people waiting to receive one through the formal process of application to social care services which can take weeks to complete. HCPs referring patients into Care Plus reported that they have been freed up to carry out their primary role and develop a more satisfactory relationship with patients around medical need. Clinicians and professionals interviewed as a part of the project overwhelmingly said that the service works extremely well and that they have a great deal of confidence referring their patients to the project and valued the on-going contact with the co-ordinator. The care plus project had at the time of the review meeting managed 62 cases, costing approximately £660 per person per year. A two year evaluative review of the Care-Plus Project assessed the following objectives: • The experiences of carers who have had access to the service • The experiences of staff that have been directly involved in the development of the service • The experiences of healthcare professionals that currently refer into service • The patterns of use among carers • The perceived value, benefit and success of the service for end referring clinicians and carers • The impact of the service for carers against measurable outcomes

- Areas for improvement, development and further growth

Care-Plus Project had a total of 86 current carers, of which 81 (NYHA Class III and IV) cases were selected for analysis in line with predetermined selection criteria. The comparative analysis of the Care-Plus caseload sample data and the control group caseload sample data revealed a number of findings:

- The Care-Plus Project model of service delivery was found to be significantly different to other social support services (e.g. generic carers service)
- There were significant differences in the usage profile in the Care-Plus group and the Control group (generic carers service) suggesting the support service delivery may need to be different for different groups of carers
- The access to support services, and time spent providing the support service differed significantly across the two groups
- The overall profile of usage for the Care-Plus group demonstrated significantly more demand for information, advice and advocacy services along with a slightly greater need for emotional support
- The increase in Bangladeshi carers within the Care-Plus group from Year 2 to Year 3 group combined with Bengali being the second preferred language suggests that the service must provide focused and targeted support to the Bangladeshi carer community

Appraisal

This was a very well thought out service intervention. It was based in a community voluntary organisation (a carer charity) rather than Health and Social Care statutory agencies because carers preferred this. The rationale behind the project was that people who are dying and their carers struggled to negotiate the health care system and were missing out on vital help and support services. Lead palliative care nurses went into people's own home identifying what people needed, working across the boundaries of Health & Social Care and persuading services to go into homes. The local nursing service welcomed this support for identifying social care problems (incontinence and excessive elderly washing bedding for example).

The intervention had the support of local GPs

- Carers were trained to do syringe pumps. There was a significant saving in hospital bed days
- Education was provided for HCPs, including advanced communication training

Education sessions for carers and patients were offered for carers & patients but uptake was disappointing. It was noted that the giving of information on a one to one basis was more effective. Some carers may have found it difficult to ask personal questions in a group context. If a HCP can gain their confidence then they are more likely to engage and learn. This reinforced the view that planning & delivering services to this group had to be tailored to their individual needs.

Tower Hamlets did not provide lifting and handling training which would have been useful to carers.

A significant saving in NHS Bed days was noted in an informal audit.

Resources available
Real choice, best care directory. An Information Pack for patients and carers which includes many details of all local agencies involved in care. (See page 113 for appraisal)

A DVD was also made with carers and patients describing HF, its symptoms and implications for care. It included real present and past carers and HCPs and comprises of 4 chapters. Although it aimed to describe what HF actually was, this was subsumed under more practical issues of caring.

Both of these have kindly been supplied by this organisation.

BHF has translated the information into several languages

BAME Considerations
Given the Tower Hamlets context, there was an initial disappointing response from the Bangladeshi community until a new Bangladeshi co-ordinator was recruited. This appointment was key to engaging this community and did not affect the engagement of white service users. This individual was exceptional, committed and knew many of the carers personally.

Accepting EoL care services for a Muslim community, directly contradicts their beliefs that no medical intervention was necessary at the end of life. However, this resulted in people suffering from painful and dangerous issues, such as bedsores which could be seen in the medical context as a neglect issue and with issues of safeguarding attached to this. The project worked with this community in an attempt to educate about these concerns.

The “COPE study” (Creativity, Optimism, Planning, and Expert Information)	The purpose of this mixed method RCT was to pilot test the HF COPE intervention for caregivers of HF patients in hospice care, in a small randomised clinical trial focusing on selected variables including: • caregiver burden • QOL • depression and anxiety • caregiver knowledge

A psycho-educational intervention. Incorporating the “Home Care Guide for Advanced Heart Disease” A study supported by the National Institute for Nursing Research (R21NR011224) (McMillan, Small et al. 2013) (Buck, Zambroski et al. 2013) 	• patient QOL • Dyadic ER visits and hospitalisations COPE specifically addresses the needs of family caregivers of hospice HF patients in terms of: • managing symptoms (dyspnoea, oedema, pain (angina or other pain), and constipation. • focussing on caregiver’s self-care • recommending the benefits of relaxation techniques • spiritual care • exercise • relationship building The COPE-HF is a problem based intervention involving problem solving training which includes: 1) three visits and six phone calls from a nurse interventionist to introduce and reinforce the method 2) a manual, the **Home Care Guide for Advanced Heart Disease**, which introduces the COPE-HF method with specific sections on symptom management to help HF caregivers devise a strategy to manage common symptoms they face 3) symptom diaries to document their regular symptom assessments Although the RCT did not find significant statistical differences between intervention and control participants on any of the measures used, a related qualitative study produced a different view of the effects of the intervention. These were that: • The intervention was more useful to those who had limited experience of caring • Depending on participants’ experience of hospice care, it shaped carers’ attitudes toward the intervention. Some preferred hospice care to manage symptoms; others took on this responsibility themselves, i.e. they were already doing what the intervention manual suggested In some cases carer responses to the Home Care Guide - which was a substantial document - implied a burden for carers. Notwithstanding this however, the intervention had interesting effects of the intervention on the caregiver’s experience, in that it affirmed what they were already doing and they felt empowered by this.

Appraisal

This study, although small and hospice based, had a heterogeneous sample including dyads of four spousal, two adult children (one daughter, one son), and one sibling caregiver. Six of the patients were male and one patient was female. Five of the caregivers were female and two were male. One of the dyads was same sex and the other six were male/female. The ages of the patients ranged from 78 – 94 years of age and length of stay in the hospice ranged from four weeks to three years.

An interesting find was that caregivers used the intervention manual for self-diagnostic purposes. One realised he was suffering from depression, another used symptom management strategies to control her own chronic pain. This highlights the need for a carer’s health assessment.

The most important findings from this study are that delaying a palliative care intervention until the patient is clearly identified as “End of Life” can result in caregivers developing their own systems of informal caregiving and symptom management. Intervening at this stage can then result in carers ignoring new information because such information may cause them undue stress on this already burdened population.

The Home Care Guide for advanced heart disease and the intervention training manual have been supplied to the MHMC project team

“BIS” (Breathlessness Intervention Service)

The Breathlessness Intervention Service (BIS) is a multi-disciplinary complex intervention theoretically underpinned by a palliative care approach, utilising evidence-based non-pharmacological and pharmacological interventions to support patients with advanced disease.

It sought to establish whether BIS was more effective, and cost-effective, for patients with advanced cancer and their carers than standard care.

A single-centre Phase III fast-track single-blind mixed-method randomised controlled trial (RCT) of BIS versus standard care with 67 participants was conducted. The control arm receiving BIS after a

Contents of BIS

Initial consultation

- Patient assessment of the impact breathlessness has on life and carers’ lives
- Things already being done to alleviate it
- Discussion about additional tools that can help, i.e:
  - Fan
  - Breathing techniques overall effort of breathing
  - Breathing retraining
  - Secretion clearance
  - Mindfulness and Relaxation
  - Acupuncture and acupressure
  - Exercise
  - Anxiety management
  - Energy conservation and activity pacing
  - Pharmacological Management
  - Psychological assessment and support

http://www.cuh.org.uk/breathlessness-intervention-service-bis/about/what-we-do

two-week wait The primary outcome measure was a rating scale for patient distress due to breathlessness at two-weeks. Secondary outcomes were evaluated: • Using the Chronic Respiratory Questionnaire • Hospital Anxiety and Depression Scale • Client Services Receipt Inventory • EQ-5D • Topic-guided interviews • The BIS reduced patient distress due to breathlessness significantly more than the control group For the majority of participants it: • Reduced fear and worry • Increased confidence in managing breathlessness • Patients and carers consistently identified specific and repeatable aspects of the BIS model and interventions that helped • How interventions were delivered was important • BIS legitimised breathlessness and increased knowledge whilst making patients and carers feel 'not alone' • BIS had a 66% likelihood of better outcomes in terms of reduced distress due to breathlessness at lower health/social care costs than standard care • BIS appears to be more effective and cost-effective in advanced cancer than standard	Intervention resources: **The Cambridge BIS Manual** The Cambridge BIS manual is addressed to clinicians and is based on evidence. It describes practical techniques for helping the breathless patient which have been tried and tested in the BIS and by other centres researching the symptom and working with breathless patients across the world. If you are interested in the BIS manual and would like to purchase a copy, contact the office via email: bis@addenbrookes.nhs.uk **The Cambridge BIS toolkit** The BIS toolkit was originally developed as a teaching tool. The BIS toolkit consists of a set of memo cards containing useful advice for both patients and clinicians. Having received very good feedback from clinicians who had been given the tool, it has been decided to improve it and make it available more widely. Available soon. Price to be confirmed. If you would like to register your interest while we are improving the tool kit, please contact bis@addenbrookes.nhs.uk **Managing breathlessness in Clinical practice** This book is an invaluable resource for those working in the respiratory medicine, oncology, cardiology and other specialties where breathlessness is commonly managed although less recognised like nephrology and neurology. It will be of help to occupational therapists, physiotherapists and specialist nurses as well as physicians. It will also be of interest to anyone who wishes to increase their knowledge of the advances in evidence that now enable clinicians to offer much improved care for those suffering with frightening symptom of breathlessness. To purchase a copy please contact, bis@addenbrookes.nhs.uk

care

(Farquhar, 2014)

http://www.cuh.org.uk/breathlessness-intervention-service-bis/about/what-we-do

BIS resources

BIS Fact Sheets

- Breathlessness: Information and commonly asked questions
- Breathing methods and positions to ease breathlessness
- Handheld fan
- Managing your energy
- Relaxation
- Shortness of breath and your diet
- Mindfulness
- Self-Hypnosis

http://www.cuh.org.uk/breathlessness-intervention-service-bis/resources/patient-information-leaflets

BIS Audio resources

Relaxation CD
Relaxation and Introduction to Mindfulness. Tracks include:

Relaxation body scan…………………………..09:15
Body relaxation…………………………………08:03
Letting go of anxious thoughts………………...07:34
Visualisation technique…………………………07:16

http://www.cuh.org.uk/breathlessness-intervention-service-bis/resources/practical-tools
bis@addenbrookes.nhs.uk

Relaxation scripts
FOR HCPs TO USE

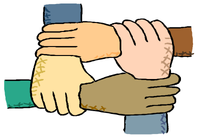
Body Scan
Letting go
Visualisation
http://www.cuh.org.uk/breathlessness-intervention-service-bis/resources/video-and-audio-help-manage-breathlessness

BIS DVD Resources

1.Causes of breathlessness
This film introduces and explains the physiology of breathlessness and the effects using male and female actors. It offers knowledge about the symptom and that, in itself, is not dangerous. It tells of strategies such as using a fan, mindfulness, CBT and other psychological techniques. It offers knowledge and normalises this symptom, so that people can gain control over their breathlessness and think about ways in which they can live with it.
http://www.cuh.org.uk/breathlessness-intervention-service-bis/resources/video-and-audio-help-manage-breathlessness

2.Using a handheld fan to reduce breathlessness
About subjective feelings of breathless and messages from brain heart and body with demonstrations and diagrams to illustrate how using a hand held fan can work. This can work as well as, or better than, oxygen therapy.
http://www.cuh.org.uk/breathlessness-intervention-service-bis/resources/video-and-audio-help-manage-breathlessness

“An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial” (Higginson et al, 2014).	This London based RCT assessed the effectiveness of early palliative care integrated with respiratory services for patients with advanced disease and refractory breathlessness including HF patients. Intervention patients received a short term breathlessness support service which was a single point of access service integrating: • palliative care • respiratory Medicine • physiotherapy, and • occupational therapy. The primary outcome was patient-reported breathlessness mastery at 6 weeks. Other outcomes were: • Mastery in the breathlessness support service group improved compared with the control group

	• Survival rate was better in the breathlessness support service group than in the control group • The breathlessness support service improved breathlessness mastery • This study provides evidence to support the early integration of palliative care for patients with diseases other than cancer and breathlessness as well as those with cancer • The improvement in survival was a particularly significant finding
“Caring for someone with End Stage HF” FILM The Princes Royal Trust for Carers. Barts and The London NHS Trust, Tower Hamlets PCT  ✡ Copies supplied with this EBS	This DVD sets out to present some of the issues affecting EoL Care for the individual dying of HF, or the ‘the cared-for person’, and is intended to provide the carer with advice on a fairly basic level. It sets out to: • Explain about HF • Introduce some of the staff the carer will meet • Talk about the end stage of HF • Explain how this is managed and the impact it will have on the life of the carer • Illustrate some of the challenges the carer may face • Provide some examples of where EoL Care can be delivered How successfully has this DVD achieved these objectives? Certainly the DVD does provide the carer with a fairly extensive guide to the kind of support available, such as respite care, alternatives to home, hospital, hospice, and so on, as well as providing good advice on dealing with some of the stresses likely to be encountered in such a situation. Useful contact numbers and details are also included. In these aspects the DVD undoubtedly succeeds. Where it does less well is in its reluctance to provide a more comprehensive illustration of what is happening physiologically in the body and mind of the dying patient. Telling us that heart-failure “…can sound quite alarming…” is surely stating the obvious. Unless one is in line for a heart transplant, end-stage heart-failure can only have one outcome. This is indeed certainly disturbing, if not outright alarming to most people whether patient or carer, even when one accepts that death is the one certainty in life. Both patient and carer need to know what is happening in some detail in order to give *both* a better chance of accepting the inevitable as well as dealing with it. It is in this area that the DVD lacks a degree of empathy and understanding.

	There is a tendency towards objectification of the person dying, referring to the 'cared-for person' as if that person is some kind of individual in an institution, rather than recognising that the person with end-stage heart-failure and the carer may share a very close personal relationship. The neglect of this relationship is, in my view, one of the shortcomings of this DVD. There is a need for a clearer breakdown of the various stages of End Stage HF even allowing for the fact that the process is not necessarily predicable. Whilst accepting that a care-plan is part of the treatment by health-care professionals, the function of a DVD such as this should be to spell out exactly what is taking place physically, in the person who has reached the final stages of life. Stating that the whole process can be "…very demanding…" is not very revealing. The DVD provides a great deal of reassurance, and in that respect it achieves some of its objectives. It is in the detail that there are limitations to the degree of usefulness which is provided. There is a clear need for a fuller discussion of the physical issues involved and a much franker examination of the processes which primarily afflict the dying person but which will also have a profound impact on the immediate carer. Appraised by JG (Honorary Fellow, University of Hull)
"Real choice" Best care directory **A directory for people with advancing illness and at the end of life** Tower Hamlets NHS PCT. St Joseph's Hospice Copy supplied with this EBS	This file is very long (comprising around 110 double sided sheets in a ring file) very detailed and complex in its compilation. Although it contains a plethora of useful information the sheer size of it could be very daunting to receive as a HF patient or carer. Sections entitled i) "About me" is useful for a family to complete in order that any visitors can immediately read about certain facts and salient issues about them. This also contains a diary for appointments. A Q&A section is also useful for patients, in terms of managing symptoms. After this however, the main section 56 pages long headed " Services" is far too dense and would be more useful to HCPs to consult in their support of HF patients and carers requirements. A shorter file, leaving out the main section, would be more useful to patients.

10.4 Good Practice programmes

Table 2 Good Practice programmes

The HF Policy Network 'Bringing HF into mainstream health policy'	On the 29th September 2015 (World Heart Day), patients, parliamentarians, and clinicians came together to demand greater recognition for HF (HF): a debilitating and costly condition, the prevalence of which is set to increase in the future. Members and supporters of a new cross-sectoral alliance, the HF Policy Network, issued a 'wake-up call' for governments across Europe in the form of a ten-point Call to Action on HF, and a supporting HF Policy Toolkit. For a video summary of the event, presentation slides, and other supporting resources, see: www.hfpolicynetwork.eu/launch2015 To sign the Call to Action, please see: www.hfpolicynetwork.eu/call-to-action
The Glasgow and Clyde experience British Heart Foundation HF Palliative Care Project Report 2006 – NHS Greater Glasgow & Clyde HF specialist nurse service (HFSNS) has been involved in a three year BHF funded supportive palliative care project. Final Report October 2010	This project aimed to systematically define a set of patients identified by the HF specialist nurses (HFSN) from their existing patient caseload who would be appropriate for a supportive palliative care approach. A framework was designed to identify, comprehensively assess and implement realistic goals of care for the patients and their caregivers. The project was staffed jointly by a HF Specialist Nurse and a specialist palliative care nurse. This partnership approach enabled the teams to share skills and support the HF Specialist Nurses (HFSNs) with joint visits and work-based learning opportunities, using the skills and experiences from the two specialties. Overall, the project aimed to consider: • whether a supportive palliative care approach can be encompassed within the existing HFSNs role, • whether patients can be identified appropriately in view of such an uncertain trajectory, and • the extent to which the supportive/palliative care needs of patients and their care givers is currently being met within the HFSNs role.

Yvonne Millerick, BHF HF palliative care specialist nurse Jackie Wright, BHF HF palliative care specialist nurse Alison Freeman, Clinical effectiveness co-ordinator, NHS GG&C https://www.bhf.org.uk/publications/about-bhf/z811-bhf-heart-failure-palliative-care-project-report---the-glasgow-and-clyde-experience	**Key findings from the project** It is achievable to integrate a supportive palliative care approach effectively into the existing HFSN role. Some HFSNs demonstrated they were able to implement this approach effectively with minimal or no support, whilst others required additional and continued support (exclusively available from within the project). It does require additional time from the nurses to take a more holistic approach to care and to engage in some of the complex conversations with patients and carers about priorities for care. Without additional time and on-going support for some HFSNs it remains unclear whether this is sustainable within the constraints of the usual service. The inclusion criterion identified a significant percentage of patients in the last months of life. A number of patients did not meet the inclusion criteria but nonetheless died during the project, many of whom were either still being optimised on evidence-based therapy or died suddenly. More work is needed to develop robust and accurate inclusion criteria and increased HFSN experience in patient identification
Better Together. An EoL initiative for patients with HF and their families Better Together: A study of the development and impact of the British Heart Foundation (BHF) and Marie Curie Cancer Care (MCCC) supportive and palliative care initiative for patients with heart failure and their families.	[18]The British Heart Foundation (BHF) with the Marie Curie Cancer Care (MCCC) established a one year pilot supportive and palliative care service in Bradford and Poole for people with advanced HF and their family carers. This was extended for a further year due to slow uptake. Patients with NYHA III or IV level were eligible. The BHF HFSNs are specialists who provide education, advice, symptom management and medication monitoring and review. Marie Curie nurses (MCNs) are trained to provide practical hands-on nursing care in the patients' homes from referral until the end of life. The aims was to examine and evaluate a new model of care consisting of collaborative working by HFSNs and MCNs in a primary care setting From September 2006, the number of MCNs and Marie Curie healthcare assistants (MCHCAs) was increased to care for patients referred from BHF's HFSNs caseloads and district nurses. Both BHF and MCCC staff received joint training in the support and palliative care of HF patients. This training was provided so that the MCNs would be able to provide physical and psychological care to patients, and administer prescribed medications for symptom relief. Care assistants would have more of a role in respite care providing practical nursing care and psychological support to patients and carers. This would enable more home based care to be provided for patients than could be provided by the HFSN team alone.

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[18] *Taken directly from Pattendon and Mason*

For the full report the PDF attached https://www.bhf.org.uk/publications/living-with-a-heart-condition/m123r-better-together---an-end-of-life-initiative-for-patients-with-heart-failure-and-their-families	The Marie Curie service is traditionally offered in the last six months of life and primarily at night, but for this pilot it was offered an estimated 12 months before death to provide respite care where necessary, and then EoL Care as the patient deteriorated. Knowing when to involve palliative care services has proved problematic for some HFSNs, with no objective criterion to help them, and complex social and contextual circumstances as well as clinical features to consider. Most HF nurses aim to use a palliative approach from when a patient comes into their caseload, but there will come a time when further support and expert care in the dying phase is needed to achieve the best quality of life for patients and their families. Patients could be referred to the new service by HF nurses, district nurses, community matrons and GPs. The estimated numbers of hospital admissions averted for HF were 14 in Bradford and 18 in Poole. The cost per HF admission averted was £1,529 in Bradford. In Poole, these averted admissions were estimated to be cost saving. The total cost of the intervention was £44,537 in Bradford and £20,908 in Poole. In Bradford, the total cost of care was significantly lower in the intervention group; in Poole, there was a trend for lower costs in the intervention group, but this was not statistically significant. Nationally, few people get to die in their place of choice. By contrast, in this study, the majority of people were cared for and died in their place of choice; at home or in a hospice. In both groups, rates of home deaths were higher in the intervention group. In Bradford, PPC was 70%, and in Poole, the corresponding figure was 77%. Some patients died in hospital. However, in the main these admissions were necessary and unavoidable: two severe falls, two strokes, one hepatic congestion and metabolic acidosis, three cancers. In four cases however, it was not possible to get a MCN at such short notice and the patients were admitted to hospital or community palliative care beds instead. **Conclusions** It is apparent that provision of supportive and palliative care for people with HF is a complex issue. An unpredictable prognosis need not be seen as a barrier to provision of EoL services for people with HF. It is possible to provide care at an appropriate time within the last year of life. This joint service goes some way to bridging the gaps in EoL Care, especially for those who wish to die at home. However, a fast response service would improve the current model of service delivery, with more day care available for respite and supportive needs.

	Despite the limitations of the study, the BT intervention shows potential for both reducing NHS costs and delivering benefits to patients. Whilst the findings are not robust enough to support implementation of the intervention into routine care, there is a case for undertaking a more rigorous evaluation, such as a well-designed randomised trial, to confirm or refute these findings. Further detailed conclusions and recommendations relating to; Service delivery, Avoiding emergency admissions, Impact on patients and families are in Jill Pattenden Anne Mason (2010).
Innovative Care for Chronic Conditions (ICCC) Framework	Two surveys over a period of 5 years have illustrated a growing partnership between HF nurses and palliative care services and that they play a pivotal role in ensuring provision of both general and specialist palliative care for their patients. The ICCC framework integrates cardiology and palliative care clinical services, and aspects of local, regional and national service provision. It constitutes an interaction between the “micro” (individual and family), “meso” (healthcare organisation and community) and “macro” (policy) levels. Self management support, delivery system design, decision support and clinical information systems are designated as key areas crucial for success in improving patient-related outcomes. Similar models of care have been used successfully in the US, and other areas of the world and these principles are mirrored in many of the UK health policies. The National Institute for Health and Care Excellence (NICE) guidelines for HF supported the appointment of HF nurse specialists (HFNSs) in every health care community,often in partnership with the British Heart Foundation (BHF) and regional cardiac networks work on key areas consistent with the ICCC framework (Breslin, Fitzsimons et al. 2014).

10.5 Final comments

HF has a poor prognosis, and while survival rates have improved over the last decade, the median survival is still around 3 years from diagnosis.(Whittingham, Barnes et al. 2013).

10.5.1 Support and interventions

Following the COPE intervention study, carer participants offered the following recommendations which had a main focus on symptom management:

- Discuss symptom management for multi-morbidity
- Design a pamphlet with information on what to expect related to symptom management with phone numbers of where to call for advice
- Have trained, lay, non-medical people available as front line symptom management coaches. Lay coaches should be able to assess a situation from a protocol, provide scripted directions, and triage more serious calls quickly to medical personnel
- Target specific groups, (those identified by hospices or people new to caring)
- Offer interventions earlier in the caregiving trajectory
- Supply an “executive summary” of the intervention (for example, in pamphlet form covering the information in the manual which would enable the caregiver to access targeted information quickly). Linking the pamphlet to readily available lay coaches on the telephone was a further recommendation
- Assess the caregiving situation at every patient visit, specifically, when there are changes in condition indicating disease progression

From the CarePlus study it is clear that carers can be trained in nursing skills such as syringe pumps. Audits have illustrated that Carers can also manage Just in Case Boxes.

NICE are proposing a cluster randomised controlled trial to compare “Just in case box” use with a generic list of medications or anticipatory prescribing individualised to the patient’s expected symptoms, compared with reactive prescribing at the bedside after symptoms have occurred. Outcomes of interest will include patient and carer symptom ratings, patient rated quality of life and healthcare use (NICE 2015).

Targeting interventions to reduce the perception of caregiving task difficulty and therefore lessening the threat that people feel about these has the potential to improve the caregiver’s QOL (Nauser, et al, 2011).

The training of Doulas, EoL Care Facilitators and volunteers was identified in the General EoL Care EBS that accompanies this HF focused EBS; it is important that when looking at education and support for carers of people with HF approaching EoL that these are kept in mind for any training and support that the MHMC project team are to offer.

10.5.2 Sudden death

- A sudden death may complicate gaining a death certification or require the involvement of the coroner. Interrogation of device data may sometimes be required by the coroner to aid clarification of the mechanism of death
- Relatives of those who die suddenly are at a higher risk of complicated bereavement
- Issues of sudden death and living with uncertainty are pertinent to all patients with HF and there should be the opportunity to discuss these issues throughout care. The palliative needs of patients and carers should be identified, assessed, offered and managed at the earliest opportunity (Al-Mohammad and Mant 2011)
- Death occurring at a time of crisis, (perhaps when a person is being transported to hospital or in an A&E department) can disrupt and distress relatives because they may not be able to access a peaceful, private place in which to take their leave

10.5.3 Carer and family needs

- Carers' needs begin at the point of a patient's diagnosis and continue into bereavement
- Evidence based knowledge is of paramount importance for patients and carers
- Carers require specific information on symptoms, implications of the symptoms, what to expect next, signs of impending death and instructions on what to do (Kehl 2015)
- Carers need to be clear in their minds about what is involved with the care their relatives are receiving and the implications of this (Doherty, Fitzsimons et al. 2015)
- Communication with patients and family/carers as well as within the clinical team is paramount. Decisions about treatment may have to be made on the patient's behalf, and the patient and family/carer may not have anticipated or thought about what care their relatives would prefer at the EoL and at which point (NHS Scotland 2010)
- Support for family and carers' varies, particularly during the patients' illness. While most carers report being dealt with sensitively after the death, around 20% report they would have liked more support following the death and 25% wanted more support from their GP (Voices survey)
- Delaying palliative care support until the patient is clearly identified as being at the "end of life", can result in caregivers meanwhile developing their own systems of informal caregiving and symptom management
- EoL Care should be available in all places of care be it the patient's home, a care home, hospice or hospital - including coronary care units where many HF patients are admitted
- Support should be holistic and include HF and palliative care specialists

PART 4. FOR HCPs & HEALTH CARE PROVIDERS

Section 11. Clinical and other guideline for the HF trajectory

ACCF/AHA guideline for the management of HF: a report of the American College of Cardiology Foundation/American Heart Association Task Force on Practice Guidelines (2013)

(Yancy, et al, 2013)

A practical guide to self-management support Key components for successful implementation

“This guide provides an overview of self-management support and the key components for effective implementation. It is for people with a role where they can implement self-management support, such as commissioners, health care professionals, service managers, people in voluntary or community groups and patient leaders. The guide will be useful both for those starting their self-management support journey and those building on and improving the support that they already provide” (de Iongh, et al, 2015, p3),

http://www.health.org.uk/sites/default/files/APracticalGuideToSelfManagementSupport.pdf

Operational Policy for the deactivation/reactivation of Implantable cardioverter defibrillator (Greater Manchester & Cheshire Cardiac & Stroke Network) (2012)
(GMCCSN) November 2012

The purpose of this document is:

- To clarify what to do and who to contact when a patient with an ICD requires deactivation or reactivation of an ICD.
- To highlight the need for all doctors, physiologists, nurses and other health care workers to be aware that discussions and decisions about deactivation of ICD need to be undertaken at the right time and before a crisis situation arises.
- To provide clarity on the type of patients with advanced progressive illness who may require deactivation.

www.gmccsn.nhs.uk/files/8113/6983/8277/ICD_Deactivation_PolicyFinal_V1.0.pdf

HFSA Comprehensive HF Practice Guidelines**. (2010)**
Lindenfield (2010).
www.onlinejcf.com

Health Foundation. A Practical Guide to Self-Management support (2015). Key components for successful implementation. Booklet for Health Providers.
(de longh, 2015).

http://www.health.org.uk/sites/default/files/APracticalGuideToSelfManagementSupport.pdf

See more at: http://www.health.org.uk/publication/practical-guide-self-management-upport?dm_i=4Y2,3W7WH,HLPDD9,E1GX3,1#sthash.XiS5saDG.dpuf

NICE Clinical Guideline. Chronic HF. (2010)
Management of chronic HF in adults in primary and secondary care

Issued: August 2010. Guideline 108
https://www.nice.org.uk/guidance/cg108

NICE clinical guideline. Acute HF diagnosing and managing acute HF in adults. (2014)
Issued: October 2014 **guideline 187**

https://www.nice.org.uk/guidance/cg187

QISMET (2015)
(Quality Institute for Self-Management Education and Training) is an independent body developed to support self-management providers and commissioners to achieve the highest possible quality service for people living with long-term health conditions. QISMET 2015 is the new updated standard to include online provision of self-management support.

http://qismet.org.uk/

11.1 NICE draft guideline consultation – care of the dying adult (2015)

NICE has commissioned, and is consulting on, a new draft guideline on Care of the Dying adult, exploring the Care of the dying adult. Draft for consultation, July 2015. Closing date: 9 September. It is intended for people who are dying, their families, carers and others important to them. 67 new guidelines are flagged up for review in 2015 and areas for further research highlighted. In addition, some clinical issues are clarified for HCPs.

This consultation process includes:
Recognising when a person is in the last days of life.

Areas to be researched further include the on-going challenge for HCPs (and patients and carers) in recognising the EoL - be it in weeks or up to seven days before death.

11.1.1Communication

Establishing the communication needs and expectations of people who may be entering their last days of life. For example:

- Discuss the dying person’s prognosis with them (unless they do not wish to be informed) as soon as it is recognised that they may be entering the last days of life including those important to them in the discussion if the dying person wishes
- Identify the most appropriate available multi-professional team member to explain the dying person’s prognosis
- Provide the dying person, and those important to them, with accurate information about their prognosis (unless they do not wish to be informed), explaining any uncertainty and how this will be managed, but avoiding giving false optimism

Shared decision making will be reviewed as will pharmaceutical and other interventions on the following EoL symptoms:

- Assisted hydration
- Pain management
- Breathlessness
- Nausea, vomiting
- Anxiety
- Agitation
- Delirium
- Noisy breathing
- Respiratory secretions
- Anticipatory prescribing

Key messages for commissioners.

Bereavement support should be integral to HF management and provision and prompt access to chaplaincy services may be important for some.

Commissioning EoL Care for HF patients is particularly challenging because the disease progression is variable and unpredictable.

Section 12 Clarifying terminology for carers

An issue for patients and carers, especially BAME carers, is understanding the terminology used by HCPs. This issue has been flagged up in earlier stages of the EBS. Recent evidence shows that this is a potential barrier to the uptake of palliative care, some carers interpreting questions about their EoL Care preferences as a question about euthanasia or suicide. Misunderstandings and myths regarding terms need unraveling. Recommendations to Healthcare Providers and Researchers Partners suggested that avoiding the use of professional jargon or terminology could significantly improve HF care (Imes, Dougherty et al. 2011).

The box below contains terms and description familiar to HCPs, the meanings of which can then be transmitted to CVD patients and their carers. As mentioned above, other terminology such as those used in dietary and lifestyle advice should also be explained.

The use of the term “HF” can be frightening to patients and family, They are unclear about what this actually means physiologically. They very often do not appreciate the gravity and nature of their condition (Barclay, Momen et al. 2011).

The definition adopted in this document of the term ‘End of Life’ is that used by the General Medical Council, that is, where death is expected within 12 months. This definition includes people with advanced, progressive, incurable conditions. http://www.nice.org.uk/guidance/qs13/chapter/quality-statement-1-identification

EoL is recognised as being one component of palliative care and concerned with a 30 day period and because things like stroke, for example, can be a sudden event (NHS Scotland 2010).

EoL Care helps those with advanced, progressive, incurable illnesses such as HF, to live as well as possible until they die. It enables the supportive and palliative care needs of both patients and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support (Princes Royal Trust 2010).

There is a national drive to improve the quality of EoL care in all clinical areas (Cowey, Smith et al. 2015). Encouraging collaboration and partnership when working with specialist palliative care services would optimise palliative care service delivery and may provide patients and their families with greater opportunities for documenting and achieving preferences for care and achieving a better quality of death (Gardiner, Harrison et al. 2013).

The National Council for Palliative Care describe **EoL care** as care that helps all those with advanced, progressive and incurable conditions to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes physical care, management of pain and other symptoms and provision of psychological, social, spiritual and practical support (Connolly, Beattie et al. 2014)

The World Health Organisation defines palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." Cited in (Ward, Donnelly et al. 2014).

Palliative care looks to address physical, emotional, spiritual and social concerns of patients who have advanced illnesses and those around them. It is a specialist branch of healthcare that instead of focusing on active interventions and treatments intended to prolong life it focuses on symptom relief and support to manage the stress and impact of serious illness for someone with a life limiting illness[19]. Palliative care looks at providing relief from physical aspects of life limiting illness. These may be many distressing physical symptoms. Emotional, spiritual and psychosocial issues are also addressed. Palliative care can provide support systems for family to help them cope, such as offering respite whilst caring for the patient. On-going support will preserve a good quality of life for both patients and their families (Ward, Donnelly et al. 2014).

Routes to symptom management are various depending on the patient. A lot of medication may be given subcutaneous that is injected under the skin as opposed to the patient swallowing this. Palliative care asserts that dying is a natural process, and addressing aspects of death that are important to the individual are examined. This could be around where the person wants to die, whether they want active treatment to stop or continue. Palliative care does not do anything to either hasten or postpone death. It is not euthanasia or assisted death and does not prolong life through artificial intervention.

Palliative care is multi-disciplinary and a whole team makes up the palliative care approach in caring for a patient and their family. This includes doctors and nurses, social workers, counsellors, Chaplaincy, pharmacists and a variety of other allied health care professionals. Factors that are addressed include loss of independence, financial insecurity, worries about the future and/or impact of feeling like a burden. Palliative care is the treatment of 'total suffering' or 'total pain' (Ward, Donnelly et al. 2014).

The philosophy of palliative care is to achieve the best quality of life, throughout the disease trajectory for the patient and their family, by providing relief and preventing suffering. However, some carers are not aware of the phrase and its meaning but open to the suggestion when they understand what it would mean to their family member (Doherty, Fitzsimons et al. 2015).

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[19] *A life limiting or threatening illness means a patient is in the last 6 – 12 months of life.*

There is a role for specialist palliative care in the terminal phase of HF and this may be provided in hospices or hospital based departments or on a consultancy basis in the community (Connolly, Beattie et al. 2014).

“hospice” - facilities or services which are especially devoted to providing palliative and supportive care to the patient with a terminal illness and to the patient's family (NICE 2015).

Section 13 Final comments

This EBS is complex because of the nature of the HF trajectory and because it covers two elements of this, living with HF and advanced HF. However, via detailed contents, it offers clear advice on the many issues carers face at all stages of the HF trajectory. The various sections cover the epidemiology of HF including how BAME affects this. Various ways of teaching and supporting carers is outlined with some interventions as examples of how these are used. There are also many films available for carers which either pertain directly to the HF trajectory, or are useful for general EoL care issues. Main issues in advanced HF are described with specific interventions and support for carers along with up to date guidelines in various aspects of HF care for the MHMC project team and HCPs. Carers are key to HF care and, should they want and be able to, they can help support their patients throughout their illness trajectory. However, they require knowledge of what each phase presents and training in the skills they may require in order to ease their burden. Many of the resources mentioned in this EBS are available via the web links provided; certain specific ‘hard copy’ resources have been presented to the MHMC project team to supplement this EBS.

It is important to ensure that this EBS is used in combination with the other EBS reviews as part of this series of work; specifically the ‘Educational support for carers of people at the end-of-life’ EBS.

Valerie Featherstone. December 2015

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