

# European Society of Cardiology Heart Failure Association Standards for delivering heart failure care

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The management of heart failure (HF) is complex. As a consequence, most cardiology society guidelines now state that HF care should be delivered in a multiprofessional manner. The evidence base for this approach now means that the establishment of HF management programmes is a priority. This document aims to summarize the key elements which should be involved in, as well as some more desirable features which can improve the delivery of care in a HF management programme, while bearing in mind that the specifics of the service may vary from site to site. We envisage a situation whereby all patients have access to the best possible care, including improved access to palliative care services, informed by and responsive to advances in diagnosis management and treatment. The goal should be to provide a 'seamless' system of care across primary and hospital care so that the management of every patient is optimal, no matter where they begin or continue their health-care journey.

**Keywords** Heart failure • Heart failure management programmes

## Introduction

Heart failure (HF) is a common chronic medical problem, which is associated with considerable morbidity and mortality.<sup>1</sup> Despite the decline in prevalence of other cardiovascular conditions, the prevalence of HF continues to rise, partly due to the changing demography of the European population and also due to better survival from cardiovascular disease earlier in life.<sup>2,3</sup>

We now have nearly 20-year worth of clinical trial results both for drugs and devices which provide a strong evidence base for treatments which reduce both morbidity and mortality in HF.<sup>3–6</sup> That evidence base has led to practice guidelines which have been published and updated as required, and these guidelines are the basis for allowing health-care professionals to deliver the best, evidence-based care to patients.<sup>7–9</sup> The guidelines are thus important tools in clinical governance. In addition, many of the

performance indicators health-care providers are measured against are benchmarks taken from the guidelines.

Despite the plethora of publications and guidelines, European community-based studies and registry data consistently show a lower uptake than expected of evidence-based investigations and therapies, and concomitantly higher rates of hospitalizations for HF and mortality than those reported in the clinical trials.<sup>10,11</sup> There has thus been a paradigm shift away from concentration on individual drug therapies to the systems of care in which treatments are delivered, i.e. within organized multiprofessional HF services.

As a result, in the last few years, several randomized controlled trials of multiprofessional/organized/managed care vs. usual care have been carried out.<sup>12–16</sup> They are heterogeneous in nature in terms of the models of care they have employed including: multi-professional HF clinics, multiprofessional follow-up without HF

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clinics, telephone contact, primary care follow-up, and enhanced patient self-care. Most have used specialist personnel including cardiologists and HF specialist nurses within the multiprofessional team. A recent systematic review of 29 of these trials showed that specialized multiprofessional care in the clinic or non-clinic setting reduced mortality by 25%, HF hospitalizations by 26%, and all-cause hospitalizations by 19%.<sup>17</sup> The vast majority of the trials of managed or systematic organized HF care have concentrated on patients who have had a recent admission to hospital with HF.

Following on from this, most cardiology society guidelines now state that HF care should be delivered in such a multiprofessional manner. The evidence now means that the establishment of HF management programmes is a priority.

In setting up an HF management programme, consideration should be given to several areas involving both content and organizational issues.

This document aims to summarize the key elements which should be involved, as well as some more desirable features which can improve the delivery care in an HF management programme, while bearing in mind that the specifics of the service may vary from site to site. We envisage a situation whereby all patients have access to the best possible care, including improved access to palliative care services, informed by and responsive to advances in diagnosis management and treatment. The goal should be to provide a 'seamless' system of care across primary and hospital care so that the management of every patient is optimal, no matter where they begin or continue their health-care journey.

The following issues are addressed:

- (i) the complexity of HF care
- (ii) general points about HF management programmes
- (iii) specific points about HF management programmes
  - (a) personnel
  - (b) the central role of guidelines
  - (c) the role of outpatient clinics
  - (d) diagnostic services
  - (e) therapeutic services
  - (f) follow-up and monitoring
  - (g) patients
  - (h) audit
  - (i) training issues

## Complexity of HF care

It is evident that the management of the patient with suspected or confirmed HF is complex and that the numbers of patients involved are large and increasing. Patients are asked to make lifestyle changes, take multiple drugs, and are exposed increasingly to device therapy. In addition, the average age of an HF patient at diagnosis is 76 years—i.e. it is predominantly a 'cardio-geriatric syndrome'. Affected patients have frequent and multiple co-morbidities. The therapies themselves have numerous side effects. In the midst of all this, the HF patient has to make multiple visits to hospital clinics often seeing numerous doctors. This can

sow the seeds of enormous confusion likely to result in patchy adherence to therapy.

It is obvious, therefore, that management cannot just be focused on one sector of care, as the HF patient can arrive in a number of health-care settings. Unfortunately, the diagnosis is still most often made during a hospital admission,<sup>2,18</sup> when the patient can present to the coronary care unit, a cardiology ward, a general internal medicine ward, or care of the elderly ward. Patients are also readmitted frequently, and during the hospital stay, they have a high mortality rate.<sup>19–21</sup> Of course, patients can also present to the general practitioner for diagnosis and survivors are discharged back into the community following admissions. Many health-care professionals with different types of expertise across a range of medical, nursing, and other professions allied to medicine together with support services in the community are thus needed to tackle HF for any given population. The need to organize services across traditional boundaries may explain why many in Europe are struggling with the implementation of organized HF care.

## Heart failure management programmes

### General points

Most HF services have unique features which are specific to their geographical location, disease prevalence, local barriers to optimal care, and resources. Essential components of successful ones include:

- specialist heart failure cardiologists;
- specialist heart failure nurses;
- an ability to function across sectors of care;
- heart failure outpatient clinics;
- adherence to common guidelines.

The goals of an ideal HF service are to provide for all patients: an accurate diagnosis; the correct investigations and implementation of appropriate evidence-based therapy; education for both the patient and their carers; with the overall aim of improving both survival and quality of life.

### Specific points for setting up heart failure services

#### Personnel

##### Medical staff

##### *Hospital cardiologists*

Studies have shown that HF outcomes are better for patients when they are admitted under specialist cardiology medical staff.<sup>22,23</sup> This is a crucial high-risk period for the patient, where the diagnosis must be clarified or revisited, reversible factors addressed, evidence-based therapies started, co-morbidities treated, and the post-discharge management planned.

Hence, we would suggest that all tertiary/teaching/university hospital referral centres should have among their cardiology staff/faculty an individual with a specific interest and expertise in HF. Although we realize that it may take some years to attain

ideal HF provision among medical staff, for a tertiary centre, 25% of the cardiology staff should have an HF remit. The target to achieve should be 1/100 000 population.<sup>24</sup>

During the next 10 years, secondary referral centres/district general hospitals with three cardiologists should make certain that at least one has a specialist interest in HF. In centres where there is only one cardiologist at present, acceptable interim alternatives would be a physician with a specific remit for provision of HF care. This person (who could either be a geriatrician or be a general internal medicine specialist) would be responsible for the setting up and co-ordination of both inpatient and outpatient management strategies for HF.

#### *Primary care*

In primary care, the ideal is to involve specialist cardiology primary care physicians<sup>12</sup> to support and ensure the optimum primary and secondary care interface for the patient. Even without such a specialist, a robust HF management programme must include the primary care physician as an important member of the multiprofessional team as they are often the first port of call for patients who have symptoms and signs which may be due to HF; hence, they are involved in the diagnostic process. In addition, they are also the health-care professionals who may be called when a patient with HF deteriorates.

#### **Nursing staff**

The value of specialist nurse practitioners in reducing subsequent hospitalizations for patients admitted to hospital with decompensated HF has been shown in a number of studies in mainland Europe, the USA, Australia, and Scotland.<sup>12–14,16,25</sup> Each acute hospital site should therefore aim to achieve the ESC target of 1 HF nurse per 100 000 of population.

The service provided by HF specialist nurses varies widely according to the site and geographical location. We strongly advise that the nurses' base, where possible, should be a site with access to a cardiologist with a specific interest in HF. The designated HF cardiologist (above) should serve as the source of medical advice when needed. The potential role of the nurse is wide and could involve home visits, telephone contact, facilitating telemonitoring, running nurse-led clinics, or a combination of these, as well as providing education for health professionals involved in the management of the patient. Their major remit should be to care for patients recently admitted with decompensated HF or those at highest risk of such an admission.

The specialist nurses' main focus should be on patient education and the optimization of medical therapy.<sup>26,27</sup> In some European countries, nurses are allowed to prescribe HF drugs, others can up-titrate prescribed medical therapies, and all should be able to liaise with a hospital or community physician, so that the initiation or optimization of therapy is possible. Heart failure nurses should also be encouraged to take part in HF clinics with a remit for 'supervised diagnosis' and optimization of therapy and education for incident and prevalent cases of HF, not currently captured by a hospital admission. The HF nursing service should be able to function as a key link between secondary and primary care.

In setting up an HF management programme, it is advisable to look at where the strengths and weaknesses lie within existing

health-care provision. There are many models of care described in the landmark studies of multiprofessional care. Some services will need to recruit specialist hospital cardiology staff and use specialist nurses in hospital linking to primary care. Others will need to bolster the community sector and increase specialist nurse input outside the hospital. Owing to geographical considerations and/or the patient population being cared for, concentrating nursing expertise to provide telephone-assisted management or facilitation of telemonitoring may be the way to proceed. It is important to remember that although there are differences between the models of care as to the magnitude and nature of the observed benefit in terms of reductions in mortality, hospitalizations, etc., any attempt at providing multiprofessional care produces benefit to patients.

#### **Multiprofessional team**

Depending on the patient population and available resources, we advise that there should be a close collaboration between HF practitioners and experts in allied health professions to form a multiprofessional team, including pharmacists, dieticians, physiotherapists, psychologists, primary care providers, and social workers.<sup>28</sup>

#### **Guidelines**

Each acute hospital in conjunction with its community services should agree local, deliverable guidelines for the management of HF in both primary and secondary care to ensure a consistent approach for patients being managed in hospital or in the community. The guidelines should also include specific medical therapy guidelines which can be used to allow nurse prescribing and optimization of therapy, if appropriate, within agreed boundaries. These guidelines should be based around the ESC and other National Guidelines regarding the specific treatments to be delivered.<sup>7</sup>

#### **The role of outpatient clinics**

All patients suspected of having HF should have the diagnosis established and then the aetiology defined prior to implementing a management strategy. All hospitals admitting patients acutely should have the necessary tools to provide this for patients admitted acutely with new HF or decompensated HF, and the service should ideally run by cardiologists.

For patients being referred as outpatients, the usual model of care is for the primary care physician to refer patients suspected of HF to a cardiologist [preferably after an electrocardiogram (ECG) and B-type natriuretic peptide (BNP) have been carried out—see ESC guidelines]. The ideal setting for establishing the diagnostic and management strategies for HF is an HF clinic with access to a specialist physician with expertise in HF. Participation of a specialist primary care physician in such clinics is ideal and is practised in some centres of excellence but it is probably not achievable in most European centres.

Heart failure clinics are a key element in the multiprofessional models of HF care in the USA which have led to improvements in health-care delivery in HF as well as a significant reduction in hospitalizations.<sup>12</sup> Such clinics should act as a focus for referral of patients admitted acutely, from primary care (both incident and prevalent cases), from HF specialist nurses, and from other secondary care physicians such as general internal medicine,

geriatrics, and other branches of cardiology. The clinics should, if possible, be multiprofessional and involve cardiologists, primary care physician, geriatricians, specialist nurses, and pharmacists, as appropriate to local needs. They should also provide a supportive milieu for those involved in the care of the HF patients and act as a forum for discussion, advice, and appropriate supervision and training of the health-care professionals involved. Clinics also facilitate better time management by the nursing service, allowing the nurses to follow-up patients who are able to attend a clinic rather than having more time-consuming home visits. Clinics allow rapid access to HF expertise for primary and secondary care physicians, other specialist health-care professionals, and patients. They facilitate early review and management of deteriorating patients.

The provision of advanced HF therapies such as CRT/D is often aided by setting up a specialist HF clinic to allow selection of patients for cardiac resynchronization therapy (CRT) in a consistent and appropriate, evidence-based manner. Such a clinic is the best setting for optimizing CRT devices both electrically and echocardiographically after implantation, as well as optimization of the patient's medical therapy (which often needs to be adjusted after a positive or negative response to CRT).

## Diagnostic services

To diagnose and manage HF optimally, certain minimum diagnostic services should be available.

- Routine haematology, biochemistry, and ECG services.
- BNP/NT-proBNP testing.
- Echocardiography. As this is the most common means by which the presence of cardiac dysfunction is defined and as it would be desirable for HF clinics to function in a 'one stop' manner diagnostically, an echocardiography service with capacity to support the clinic should be available on site. There should be high-quality echo capable of commenting on both systolic and diastolic function, valve disease, and dyssynchrony.
- To establish the aetiology of HF, there should be access to exercise testing and coronary angiography, if indicated.
- For centres dealing with the management of advanced HF and transplantation, there must be provision for nuclear cardiology, exercise testing with oxygen uptake measurement, right heart catheter haemodynamics, and cardiac biopsy.

Diagnostic services which will be required in the near future will include more widespread access to cardiac magnetic resonance imaging.

## Therapeutic services

- All HF services should offer evidence-based drug therapy according to National Guidelines.<sup>7</sup>
- Physicians should have access to cardiac surgical services for revascularization surgery in patients with left ventricular (LV) dysfunction, as appropriate.
- There should be a referral pathway for patients to be assessed for, and implanted with a defibrillator (ICD), where indicated.

- Specialist centres should be able to offer CRT for relief of symptoms in suitable patients. If not available on site, there should be a pathway for referral for CRT.
- A referral strategy should be in place for patients who require.
- Transplantation and/or LV assist device therapy.
- Palliative care.<sup>29</sup>
- Cardiac rehabilitation.

## Follow-up and monitoring

This is a neglected area of HF care with little evidence available from the literature to guide us. Some of the guidelines advocate follow-up for HF patients who are stable on a 6 monthly basis to check symptoms and blood chemistry. Other patients, of course, must be seen more frequently while they are having up-titration of medical therapy, when they have had a recent hospital admission or when they have increasing symptoms requiring escalation of medical therapy, consideration of device therapy, or assessment for transplantation. In addition, after intensification of therapy or implantation of devices or listing for transplant, more rigorous follow-up is required.

Once again, the optimum milieu for follow-up is within a multi-professional HF clinic, to which patients can have easy access. Apart from general clinical monitoring, we have little evidence to support specific monitoring tools, although many studies are currently underway which may inform our practice in the future. To date, we do not have enough evidence to advocate serial monitoring with either BNP or an echocardiogram, although both may be indicated when we suspect clinical deterioration to help intensify therapy.<sup>30–32</sup> Recent telemonitoring studies also seem to show positive effects and will no doubt be incorporated into clinics in the future.<sup>33</sup>

## Patients

Disease management programmes for HF were established with the primary aim of reducing morbidity. Accordingly, they initially focused attention on patients at the more severe end of the spectrum and demonstrated positive results, including a reduction in rehospitalization, improved quality of life, improved utilization of proven therapies, and lengthened life expectancy, all at reduced costs. In contrast, there are few data addressing the benefit of HF services in the earlier stages of HF. While lacking a firm evidence base, it seems reasonable to advocate that all patients with HF should be able to access the benefits of organized HF care. Examples of other HF patients who may benefit are as follows.

(i) Those with a new diagnosis of HF: the new presentation of HF is often first assessed by a general practitioner. At this early stage in the natural history of HF, the diagnosis can be difficult, reflecting the non-specific nature of the symptoms and lack of physical signs. Misdiagnosis and delay in appropriate therapy and investigation are common as well as potentially exposing the patient to unnecessary therapy. Experience from specialist-led diagnostic clinics has shown how the correct diagnosis can be expedited, resulting in earlier initiation of appropriate therapy.

(ii) For those with established HF: an annual review. There are now several good reasons to propose that all HF patients, irrespective of their clinical status, should have a specialist review

once a year in a multiprofessional management programme. (Clear exceptions to this generalization include those in the terminal phase of the syndrome or in whom other conditions will significantly limit life expectancy.) As HF management is rapidly changing, new therapies, both medical and device-based, are being approved at regular intervals. It is becoming increasingly difficult for non-specialists to keep pace with these changes, underlining the value of specialist review to maximize the opportunity for all patients to benefit from advances where appropriate. Furthermore, it is also possible that patient adherence to self-care strategies and compliance with therapy may wane over time and an annual review with a specialist service will provide an opportunity for members of the HF team to revise important issues.

### Audit

Being able to evaluate an HF management programme is essential. A defined data set of variables which must be collected is invaluable for auditing quality of care, assessing the implementation of changes in a programme, and allowing trends to be evaluated. Ideally, a data set should form the basis of a database to facilitate data entry and may even evolve into an electronic patient record. Such systems then enable a description of the process of care whether in randomized trials, observational studies, registries, or for quality improvement initiatives in patient care. Many national societies affiliated to the ESC have developed such data sets, which should be available to consult when setting up an HF programme.

Evaluation of the programme should ideally take into consideration both its organization and the patient perspective.<sup>34</sup>

Organization-oriented evaluation examples include:

- time from referral to patient’s visit at the clinic

- staff competencies
- readmissions
- mortality
- device implant rates

Patient-oriented evaluation examples:

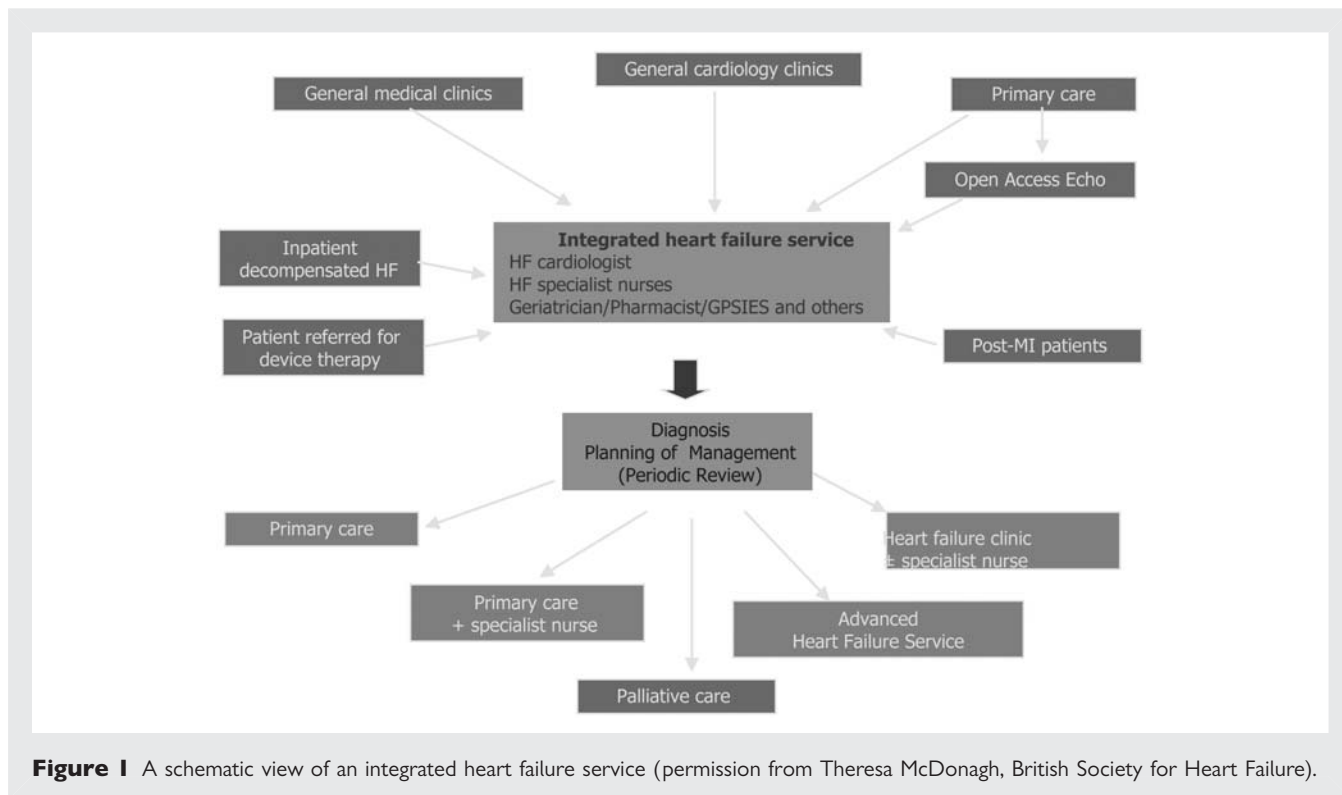
- reached goal doses of therapy
- reached patient goals (individual)
- patient’s wellbeing (symptoms)

The assessment of each patient’s ability for self-care should be made and be the basis for the agreement of individual goals, such as weighing each day or learning how to self-administer diuretics when needed. This can be evaluated formally using the European Heart Failure Self-care Behaviour scale.<sup>35</sup> Patients’ symptoms and wellbeing can be evaluated by means of a five-point Likert scale on which the patient assess his/her intensity of breathlessness, fatigue, or pain at each visit.<sup>36</sup> Another instrument focusing on symptoms is the Kansas City cardiomyopathy questionnaire (KCCQ) which is sensitive to changes in a patient’s condition and also covers quality-of-life items.<sup>37</sup>

It is also important to establish whether the patient has symptoms of depression which may impact on their response to multi-professional care strategies and require special attention.<sup>38</sup>

### Training issues

To help increase the number of HF specialists, both nurses and doctors needed to construct HF management programmes, long-term planning for training has to be established. Already many jobs for health-care professionals have a specific HF remit, and there will be a steady increase in such jobs over the next few years.



**Figure 1** A schematic view of an integrated heart failure service (permission from Theresa McDonagh, British Society for Heart Failure).

Training and revalidation for both cardiologists and nurses within ESC countries is delivered nationally but there is scope to develop ESC wide curricula to ensure consistency of training and to facilitate movement of health-care professionals between ESC countries.

For cardiologists, some countries are further ahead than others in developing subspecialty accreditation. It is, for example, available in the UK.

For nurses, many ESC countries have well-established HF specialist nurse courses. The HFA and the CCNAP of the ESC are sponsoring the development and implementation of wide HF nurse curriculum.

## Conclusion

An HF management programme setup as outlined here will be available to the HF patient wherever they enter their health-care journey. The subsequent management for most will be in primary care, mediated by an HF nurse and the primary care physician with cardiology liaison from secondary/tertiary care.

Some will need to attend HF clinics for more intensive management. Others will need access to more advanced HF care for consideration of device therapy and rarer and more rationed therapies such as cardiac transplantation and LV assist devices. Selected patients will require palliative care services.

The net result is actually a network of care pathways for the patient which fulfils the aim of improving their outcomes, regardless of their entry point to health care (see *Figure 1* for a template of an ideal HF service/network).

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