



**The Heart
Failure Policy
Network**

Pressure point 3: Clinical management



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About the Heart Failure Policy Network

The Heart Failure Policy Network is an independent, multidisciplinary group of healthcare professionals, patient advocacy groups, policymakers and other stakeholders from across Europe whose goal is to raise awareness of the unmet needs surrounding heart failure (HF) and its care. All members donate their time for free. All Network content is non-promotional and non-commercial.

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1. Top five things you need to know

1 Management of heart failure (HF) is lifelong. People living with HF have a continuous risk; they often develop comorbidities, and death may be sudden and unexpected.¹ People with HF need their condition to be closely monitored and managed to maintain general health and prevent complications, even when their condition is stable.

2 Clinical management requires a comprehensive approach with multiple goals: to manage symptoms, promptly identify and respond to exacerbations, reduce risk factors including cardiovascular risk, and generally prevent or minimise further damage to the heart.²

3 HF clinical management is best delivered by a multidisciplinary team led by an HF specialist.^{1,3} Care should involve cardiologists (ideally HF specialists) and HF specialist nurses, as well as internal medicine physicians, GPs, primary care nurses, physiotherapists, dieticians and the patient's family and carers. Other specialists should also be involved for management of any comorbidities that may be present.

4 HF management programmes are the gold standard for long-term multidisciplinary care of HF. They combine medical and device management with other protective and supportive strategies, such as cardiac rehabilitation, patient education and psychological support.⁴ They also facilitate access to care, namely acute care in episodes of decompensation.⁵

5 Leading models are underused despite having clear benefits. Persistent barriers to HF management programmes include limited financial investment, staff shortages and administrative hurdles.^{5,6} For example, in Europe, less than half of all cardiovascular patients, including chronic HF patients, access cardiac rehabilitation, a key component of HF management programmes.⁷

 **See section 2:**
What is the issue?

 **See section 5:**
Involving a multidisciplinary team

 **See section 4:**
What is good practice?

 **See section 6:**
What is happening, and why?

2. What is the issue?

HF management is complex

HF is a lifelong condition – diagnosis and initial treatment are only the start of the healthcare journey for patients.² Every person with HF requires long-term clinical monitoring and management to maintain general cardiovascular health and prevent further damage to the heart, even when their condition is stable.²

HF carries a continuous risk

HF is almost always caused by underlying damage to the heart. Even when judged suitable for discharge after an acute episode, patients remain at considerable risk; mortality at one year is 17% for hospitalised patients and 7% for those stable in outpatient care.¹ Death may be sudden and unexpected (especially in people with less severe symptoms),¹ which may be mitigated by the right package of care and support.

There are several goals to HF care

Vital goals of HF care should be to manage symptoms, prevent disease progression, maximise capacity of the heart at rest and during physical activity, improve quality of life and survival, and prevent hospital admission.¹ Patients require regular consultations to assess symptoms, adjust medication and assess the need for device treatment and monitoring.^{1,8}

Multiple comorbidities in HF patients make a multidisciplinary approach essential

Most HF patients have comorbidities; for example, around one in three HF patients has diabetes, and close to one in five has chronic obstructive pulmonary disease.⁹ Comorbidities can make achieving optimal care much more challenging. They add complexity to clinical decision-making and goal-setting, making communication across care settings and individual judgements even more important.^{10,11}

See PP:
Presentation
and diagnosis

See PP:
Discharge and
early follow-up

3. Evidence of effectiveness

Research has consistently shown the return on investment from comprehensive and collaborative management of HF:

- HF management programmes delivering multidisciplinary care reduce the risk of hospitalisation.¹²⁻¹⁴
- Home-based and clinic-based HF management programmes have been shown to reduce all-cause hospital readmission over three to six months by 25% and 30%, respectively.¹⁵
- HF management programmes can reduce mortality and healthcare costs, and improve quality of life for people living with HF.^{5,12-14} Trials conducted in Austria showed that comprehensive, multidisciplinary HF management reduces HF hospitalisations and all-cause mortality and is cost-effective compared with usual care.⁵
- Being admitted to a cardiology ward or having a cardiology follow-up (i.e. care with HF specialist involvement) are predictors of lower mortality at one year after hospital admission.¹⁶
- Cardiac rehabilitation programmes and exercise-based interventions have been independently proven to be effective in reducing hospitalisations and improving quality of life.^{17,18}
- Cardiac rehabilitation may also reduce mortality;^{17,18} the 2017 National Heart Failure Audit in England and Wales showed that survival of HF patients referred to cardiac rehabilitation was 12% higher than that of those not referred to such services.¹⁹

4. What is good practice?

HF management programmes are the gold standard of care

Guidelines recommend that all HF patients be enrolled in a management programme led by a multidisciplinary team.^{1 20 21} Such programmes aim to provide 'seamless' care over the patient pathway: from discharge planning through to specialist follow-up and long-term monitoring, spanning primary and secondary care.¹ They should include:

- a comprehensive care plan ensuring regular contact points and rapid access to care in moments of worsening disease
- follow-up after discharge (regular clinic and/or home-based visits; possibly telephone support or remote monitoring)
- continuous assessment of changes in risk factors, symptoms (such as shortness of breath), signs (such as weight gain), functional status and quality of life – and provision of a suitable response in each case
- regular review and optimisation of medication and devices
- therapeutic education to encourage self-care behaviours and help optimise adherence to medication and exercise plans⁵
- psychosocial support to patients, their families and carers
- access to advanced treatment options, as appropriate.^{1 22}

HF clinics are the typical setting for organisation of HF management programmes

HF clinics are effective models for provision of specialist-led HF management programmes.^{3 5} European guidelines recommend that HF specialists lead the management of HF from the point of hospital admission,²⁰ and one successful model that is common in HF clinics is for care to be led by HF specialist nurses. In such models, the specialist nurses are responsible for routine patient liaison and monitoring under specialist physician guidance, often in outpatient premises.²³ Specialist nurse-led HF clinics are possible for patients who are relatively mobile and in a good-enough state of health.²⁴

More flexible models of care can also be beneficial

HF management programmes and HF clinics have been prioritised for high-risk symptomatic patients.^{1 5 12 22} However, many leading commentators advocate for the use of programmes for most patients, not only those at high risk.^{2 6 9} More flexible models of care can also be beneficial; current trends indicate that traditional clinic models can be successfully adapted to 'hybrid' models. These may include part-time clinics, home visits, structured telephone calls and telemedicine platforms,¹⁴ which are logical ways to expand access to HF specialists.

Close and ongoing collaboration between professionals and patients is essential

A multidisciplinary approach is needed throughout all phases of care.^{1 23 29} The multidisciplinary team should ensure clear communication; it should listen to and integrate patients' needs and wishes when developing a care plan – for example, using structured listening exercises – and closely involve individuals in clinical care decisions.^{1 20 30} Clear protocols for referral, information-sharing and scenario-planning should be available for patients and all members of the care team.¹ The team should include not only those looking after the patient's HF, but allied health professionals such as care coordinators, dieticians, physiotherapists and specialists responsible for management of comorbidities. Patients and professionals should respect one another's expertise and motivations, and work to build therapeutic alliances.



See PP:
Discharge
planning and
early follow-up



See PP:
Patient
empowerment
and self-care



See PP:
Advance care
planning



See section 7:
Case studies
and
reproducible
tools



See section 5:
Involving a
multidisciplinary
team

5. Involving a multidisciplinary team

People living with HF should be managed by a team of healthcare professionals from both primary and specialised care settings to provide optimal long-term management.³

 Role	Patient	Carers and family	Cardiologists	Internal medicine specialists and other specialists	Primary care physicians	HF specialist nurses
 Responsibilities	<p>People living with HF are often seen as core members of the multidisciplinary team. They should be closely involved in all important clinical decisions, as well as the development of the care plan, which should seek to understand the individual's circumstances, align with their wishes and clarify key points of contact in the care team.^{20 30 31}</p>	<p>Carers and family members play a huge role in psychological care and support to the person living with HF.³² They can help people learn self-care behaviours and engage with their own care.</p>	<p>Cardiologists are ideally responsible for the overall management of HF, including planning and initiation of the therapeutic strategy.³³ They are usually up to date with therapeutic recommendations and can ensure guideline-compliant care across the multidisciplinary team. Cardiologists should be consulted at key review points (for example, when the patient's condition changes or there are ambiguities in best care approaches), but regular follow-up should not be provided exclusively by them.³⁴⁻³⁶</p>	<p>Specialists other than cardiologists may often be responsible for the overall management of HF patients. This role frequently falls on internal medicine specialists,³⁷ particularly in southern European countries. Depending on the specific needs of the patient, other disease specialists may need to be engaged – for example, nephrologists if the patient has kidney disease or pneumologists if the patient has chronic obstructive pulmonary disease.</p>	<p>GPs have a key role in managing HF; they are often the first clinician to assess the patient when disease worsens and are commonly involved in titrating treatment.²⁹ Yet GPs may struggle to stay up to date with the most recent guidelines, may be less familiar with the very specific needs of people living with HF, or may lack the time and resources to manage people living with HF effectively.^{29 38} GPs and other primary care professionals often need to collaborate with specialists to ensure the adequate management of HF, which is even more critical in the presence of comorbidities.^{3 10 11}</p>	<p>HF specialist nurses have an in-depth knowledge of HF and the needs of people living with HF, and they are recognised by patients for their unique contribution.^{3 6 9 10 30 39} They can support the individual, identify the need for referral to specialist services, and are a key link between primary and secondary care, taking on a role of case manager. They can provide care in the hospital, an outpatient clinic, the patient's home, and even via telephone or other digital means.</p>

Involving a multidisciplinary team (cont.)



Role

Primary care nurses

Physiotherapists

Pharmacists

Psychologists



Responsibilities

With suitable support from other healthcare professionals, primary care nurses can assist with many aspects of regular monitoring of people living with HF and can help to educate them and their families on core self-care behaviours. They can provide care in primary care facilities, in home visits or via telephone support.²³ They can collaborate with both GPs and HF specialist nurses³⁹ to ensure each individual receives the most appropriate and responsive care.

Physiotherapists are key professional staff for cardiac rehabilitation programmes. They may lead other complementary efforts beyond physical rehabilitation, such as self-care education for behavioural changes, and motivational and psychological support.^{40,41} They can support the development of a personalised care programme.

Pharmacists may have routine interactions with patients (for example, when patients pick up prescriptions) and can support people with adherence to treatment, administrative errors in prescriptions, adverse drug reactions and risks of polypharmacy.⁸ They can support the person living with HF and the multidisciplinary team in a structured fashion to ensure understanding of medicines' interactions and the development of the best pharmacological plan for each one.

Psychologists can support people living with HF in reconciling themselves to diagnosis, and in developing new goals, ambitions, personal resilience and motivation to deal with the burden of the disease. They can teach the person's family to best support them by anticipating and mitigating psychological pressures.

6. What is really happening, and why?



See PP:
Discharge
planning and
early follow-up



See PP:
Patient
empowerment
and self-care

HF care is often fragmented and suboptimal

HF care often fails people in the weeks and months after diagnosis. Despite proven best-practice models, the reality for many patients is one of fragmented and incomplete care. Patients and carers are sometimes left unclear as to their care needs, and experience poor follow-up.^{19 42}

Primary care physicians are often not fully aware of HF treatment options; their prescribing practice (rate of prescription, and dosage) is frequently below guideline recommendations.²⁹

Multidisciplinary care is not consistent practice

Many people living with HF are managed by GPs alone, without the support of a multidisciplinary team.⁴³ However, GPs often do not have the time and resources to manage HF patients effectively.³⁸ The true potential of HF care in a primary care setting is sometimes hindered by the limited number of HF specialist nurses, as mentioned by several HF experts.

Uptake of best-practice models of care remains suboptimal

Even though HF guidelines have recommended disease management programmes since the 1990s, there are still barriers to implementation, including limited financial investment, staff shortages and administrative hurdles.^{5 6} Possibly the biggest barrier is lack of a clear, universally accepted structure for HF management programmes.

Cardiac rehabilitation remains underused

Cardiac rehabilitation has not been equally adopted in different countries.²⁵ Worldwide, fewer than 40% of countries have implemented and use cardiac rehabilitation;^{44 45} in most European countries, less than half of all cardiovascular patients, including people living with HF, access cardiac rehabilitation.⁷ For example, in England and Wales, fewer than 20% of HF patients admitted to hospital are referred for cardiac rehabilitation.¹⁶



Why is access to cardiac rehabilitation so low?

There are multiple reasons behind poor access to cardiac rehabilitation. Worldwide, there is a need to increase the number of units providing cardiac rehabilitation, as resources do not meet the demand for these programmes.^{44 45}

The low proportion of patients attending cardiac rehabilitation programmes may be due to factors including limited provision of such services; limited referral; and inadequate legislation, funding, professional guidelines and information systems.⁷ In the UK, limited access is reported to result from a lack of availability of cardiac rehabilitation services, non-systematic referral, discrepant and non-evidence-based inclusion and exclusion criteria, and a wide variation in service models with divided opinion about ideal service structures.⁴⁶ Up to 43% of cardiac rehabilitation providers in England, Wales and Northern Ireland do not accept HF patients.⁴⁶

One of the barriers to the development and consistent provision of cardiac rehabilitation is the lack of guidelines defining their optimal structure and content. In the Netherlands, the lack of best practice for exercise-based cardiac rehabilitation for people with HF led to the development of guidelines by the Dutch Royal Society for Physiotherapy, which were published in 2015.⁴⁰

7. Case studies and reproducible tools

This section presents case studies from across Europe of innovative and best practice in clinical management of HF, alongside tools available to assess long-term care.

Case studies



Redesigning the HF care pathway, NHS Foundation Trusts, UK

Two London hospital trusts (Guy's and St Thomas' NHS Foundation Trust and King's College Hospital NHS Foundation Trust) are developing a project to redesign the HF pathway, to ensure close liaison between specialists and GPs managing HF patients, and to develop education sessions and 'virtual clinics'. The project, which will cost £1.5 million, aims to reduce costs to the National Health Service by approximately £500,000 a year, save up to 80 lives a year, reduce annual bed days by 3,000 and improve patients' quality of life.⁴⁷



HF care in the community, Community Heart Failure Management Programme, Ireland

The west of Ireland developed a model of HF care, the Community Heart Failure Management Programme (CHaMP), where HF specialist nurses follow-up with patients.⁴⁸ Each nurse provides services in several primary care locations across County Galway and in home visits.⁴⁹ One of the nurses in the programme is a prescribing nurse, which has been essential for the full realisation of the benefits of the programme.⁵⁰ HF specialist nurses provide structured education, treatment aligned with clinical guidelines and interventions supportive for the person living with HF and their family. They can refer patients to a specialist if needed, which reduces the waiting time for the appointment. This innovative service ensures that patients are consistently monitored and treated in a timely manner within their own community and in collaboration with hospital services.⁴⁹⁻⁵¹



Mecor software for telecoaching and telemonitoring, Health Care Systems GmbH, Germany

The Mecor programme from Health Care Systems GmbH provides a platform for telecoaching and telemonitoring of people living with HF.⁵² The telecoaching services include education, advice and personalised coaching. For monitoring of signs and symptoms, participants weigh themselves every morning on the Mecor scale, which sends data to the telemonitor. They can register symptoms by answering yes/no questions on the monitor, and if the algorithm detects worsening disease it sends a signal to a trained nurse. The nurse decides whether it is necessary to contact the person with HF, for example reminding them to adhere to the medication plan or advising them to see a doctor. The patient decides whether they want the doctor to receive a report of the situation that called for the unscheduled appointment.⁵²



Integrated Care Pilots, British Heart Foundation, UK

The British Heart Foundation has set up nine integrated care pilot projects across the UK.⁵³ In one of the pilot regions, East Cheshire, the project includes new HF pathways and outpatient clinics, multidisciplinary assessments, care planning and home visits. Primary and secondary care physicians, including GPs and nurses, have received HF training. Across the 26 sites in the region, the community HF teams have led to a 35% reduction in hospital admissions, reaching savings estimated at £169,000 per 1,000 patients.⁵³



HF management programme, Insuffisance Cardiaque en Lorraine, France

The Insuffisance Cardiaque en Lorraine (ICALOR, Heart Failure in Lorraine) was an HF management programme created to reduce HF morbidity, mortality and rehospitalisation, and improve quality of life for people living with HF in Lorraine, France. The programme promoted coordinated and standardised care, ongoing education and support, and monitoring at home.⁴ Data were stored in electronic health records and shared across the care team, including the GP. The programme was cost-effective, reducing mortality and hospital readmission. However, it was shut down due to inefficient policies and lack of funding.^{4 55}



Increasing communication across care settings, healthcare system of the Basque Country, Spain

Osakidetza, the healthcare system of the Basque Country, Spain increased communication between primary and secondary care of HF patients by developing multidisciplinary teams coordinated by the Department of Cardiology at the University Hospital Alava.⁵⁷ The programme trained one physician and one nurse of each primary care team on management of HF, and they were then responsible for training their own teams. The programme, however, lacks assessment and follow-up.



Telemonitoring in the Management of HF, Belgium

The TElemonitoring in the MAnagement of Heart Failure (TEMA-HF 1) study assessed a telemonitoring intervention for HF care in seven hospitals across Belgium.⁵⁴ The intervention followed a collaborative approach between GPs and an HF clinic. Using telemonitoring, people living with HF were monitored daily with electronic devices, results were sent automatically to an online database, and GPs and the HF clinic received alerts if results were outside set limits. People with HF managed with this system had reduced mortality, fewer days hospitalised and fewer days in dialysis compared with patients in usual care.



Training for primary care professionals, Deventer Hospital, the Netherlands

The Deventer Hospital in the Netherlands has developed a training programme consisting of education meetings for GPs.⁵⁶ The meetings are organised for a small number of GPs, who are joined by an HF nurse and a cardiologist. This initiative has increased communication between different levels of care.



Nurse-led HF management programme in primary care, Barcelona, Spain

Healthcare institutions in the Litoral Mar area in Spain and the Catalan Health Service developed a multidisciplinary and integrated HF care model for primary care. Following discharge from an acute HF episode in any hospital in Catalonia, patients were admitted to the nurse-led multidisciplinary programme, which integrated hospital and community resources.¹³ The programme reduced the risk of readmission and death. A nurse-based telemedicine component has been added to the programme to follow-up high-risk patients, which contributed to reducing hospital readmission, length of hospital stay at readmission and costs per patient after six months of follow-up.¹⁴ This care model is being implemented and improved in South Metropolitan Barcelona with coordination from Bellvitge University Hospital.⁵⁸



HF integrated programme, Maastricht University Medical Centre, the Netherlands

The Maastricht University Medical Centre developed a programme that integrates primary and secondary HF care. It includes visits from specialist clinicians to primary care practices to educate primary care clinicians about optimal care. The specialists collaborate with primary practices making use of the HF care programme.⁵⁹



HF care pathway with telemonitoring, University Medical Center Utrecht, the Netherlands

The University Medical Center Utrecht has developed an HF care pathway where an HF specialist sees people living with HF in an outpatient clinic.⁶⁰ The pathway includes a telemonitoring component to support monitoring at home, and it may be invasive (via an implanted device) or non-invasive. The specialist nurse monitors signs and symptoms of HF, provides self-care education and support, and titrates medication if needed. The service is supervised by HF specialist cardiologists, and involves other professionals such as GPs, social workers and dieticians. The pathway also offers access to cardiac rehabilitation. Evaluation of the programme with the ICHOM HF Standard Set is planned for 2019.



HF pilot projects, HF Working Group of the Polish Cardiac Society, Poland

The HF Working Group of the Polish Cardiac Society has developed efforts to raise the profile of HF and the need for integrated HF care with the Ministry of Health. Together with associations of GPs, the group is planning to launch pilot projects of multidisciplinary and integrated care in five hospitals in different cities in 2019.⁶¹ The project considers:

- training of GPs on HF clinical guidelines
- the creation of networks of GPs to better organise HF care
- training of primary care nurses by specialist HF nurses.

The project will quantify patients' needs to develop a sustainable reimbursement model for HF care in Poland.



Understanding HF and developing value-based care, Azienda Zero, Clicon and Novartis Pharma, Italy

Azienda Zero (the healthcare system of the Veneto region in Italy), CliCon (an organisation focused on outcomes research) and Novartis Pharma initiated a three-year pilot project in 2017 to understand HF in the region⁶² and to develop HF value-based care models.⁶³ The project was initiated with an in-depth analysis of the continuum of HF care to identify gaps, inefficiencies and financial needs. It now aims to implement a new model of care to address the identified challenges. Evaluation of the revised model of care is planned for one year after full implementation. All care units will develop reports for interim assessment every three months, including, for example, number of clinical visits and medication plans per patient.



Multidisciplinary care team panel, Pleven and Sofia, Bulgaria

The need for collaboration in HF care led to the development of multidisciplinary group discussion meetings at the Medical University Pleven and Second City Hospital in Sofia, Bulgaria, making use of optimal features of the hospitals' IT system.⁶⁴ The multidisciplinary group includes doctors from a wide range of specialties. Treatment of patients with complex HF with comorbidities is discussed at the multidisciplinary meetings. So far, the meetings have helped improve diagnosis and treatment strategies in several cases.⁶⁴ They take place every day, although the condition of any given patient is only considered for discussion again if it deteriorates and a new strategy is needed.

Tools for assessing long-term care



Assessing HF care, Heart Failure Tool, UK

The Clinical Effectiveness Group of the Centre for Primary Care & Public Health at the Blizard Institute Queen Mary University of London developed the Heart Failure Tool.⁶⁵ This tool provides key diagnostic and treatment indicators in a simple format to help achieve better patient care and better quality and outcomes framework points.



Marvellous Map of Heart Failure, My Marvellous Check-up and Me, and CRT and ICD Pre implant, Pumping Marvellous, UK

The Marvellous Map of Heart Failure, developed by Pumping Marvellous in the UK, is used to understand treatments and services along the HF journey.⁶⁶ The map reflects the possible care stops that the patient can access on their own journey. Each stop represents treatment and services that are available through the National Health Service for those living with HF.

My Marvellous Check Up & Me is another tool from Pumping Marvellous for patients and healthcare professionals. It supports understanding of how the person living with HF is feeling.⁶⁶

Pumping Marvellous also developed an interactive tool that supports the user to understand cardiac resynchronisation therapy pacemaker and implantable cardiac defibrillator in HF – the CRT and ICD Pre implant tool.⁶⁶



BCN Bio-HF calculator, Spain

The Institute for Health Science Research Germans Trias i Pujol in Catalonia, Spain developed the BCN Bio-HF calculator.⁶⁷ It is a multivariate risk model to predict one-, two- and three-year mortality in HF patients. The factors in the model are easily accessible clinical characteristics, routine laboratory parameters, treatment and results of biomarkers tests.



HF Standard Set, international

In 2016, the International Consortium for Health Outcomes Measurement (ICHOM) developed a Standard Set for HF.⁶⁸ Standard Sets are disease-specific indicators to support the evaluation of care based on selected outcome measures. They aim to improve care, demonstrate superior performance and enable value-based reimbursement of interventions.⁶⁹ ICHOM provides support to the implementation, and institutions that implement the Standard Set collect the data themselves.⁷⁰



Tool: HF360 Platform, international

The HF360 Platform supports the development of HF multidisciplinary care programmes to improve management of HF in the transition period from hospital to community care.⁷¹ The platform has nine tools: a 'getting started' guide; a booklet for assessment of patient risks and needs; a guide to support monitoring; a booklet defining responsibilities in a multidisciplinary team; a booklet with guideline-recommended treatments; a guide for discharge management; a booklet with resources for patients; a guide on performance indicators; and case studies. The tools are a combination of online and downloadable content.

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