

LIVING WELL WITH HEART FAILURE

An Information Booklet for Individuals, Families and Health and Care Professionals in the UK

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Contents

1. Introduction
2. What Is Heart Failure?
3. Burden and Prevalence: Worldwide and UK
4. Risk Factors and Aetiology
5. Impact of Heart Failure on Individuals and Families
6. Evidence-Based Treatment in the NHS
7. Theoretical Models and Frameworks
8. Local and National Political Agendas
9. Recommendations for Person-Centred Care, Self-Management and End of Life Care
10. Conclusion
11. Reference List

1. Introduction

This booklet has been written for people living with heart failure, their families and carers, and the health and care professionals who support them across the UK. Heart failure is one of the most common, most disabling and most costly long-term conditions managed by the NHS, yet public understanding of it remains limited and inconsistent (McDonagh et al., 2021). The purpose of this booklet is to explain, in accessible language, what heart failure is, how common it is, who is affected, and what can be done — by services, by families and by individuals themselves — to live as well as possible with the condition. In line with current UK policy, the booklet places the person, rather than the disease alone, at the centre of care (NHS England, 2019; Welsh Government, 2025).

2. What Is Heart Failure?

Heart failure is a complex clinical syndrome, not a single disease. It occurs when structural or functional abnormalities of the heart mean it can no longer pump enough blood to meet the body's demands, or can only do so at an abnormally high filling pressure (Behnouth et al., 2023). It typically presents with breathlessness, fatigue and ankle swelling, caused by fluid build-up and reduced exercise tolerance (National Institute for Health and Care Excellence [NICE], 2025).

Clinicians classify heart failure according to left ventricular ejection fraction (the proportion of blood pumped out of the heart with each

contraction): heart failure with reduced ejection fraction (HFrEF, EF below 40%), mildly reduced ejection fraction (HFmrEF, 41–49%) and preserved ejection fraction (HFpEF, 50% or above) (McDonagh et al., 2021). This distinction matters because treatment pathways differ substantially between the three subtypes (NICE, 2025).

Key facts for readers

- Heart failure is a syndrome caused by an underlying heart problem, not a diagnosis on its own.
- Common symptoms: breathlessness, tiredness, and swollen ankles or legs.
- Around half of all cases now involve a preserved ejection fraction (HFpEF), which is harder to treat (McDonagh et al., 2021).

3. Burden and Prevalence: Worldwide and UK

Heart failure has been described as a global pandemic. Estimates place the worldwide prevalence at more than 64 million people (Savarese et al., 2023), while Global Burden of Disease modelling suggests the number of prevalent cases more than doubled between 1990 and 2021 as populations age and survival after heart attacks improves (Lippi and Sanchis-Gomar, 2020). The condition carries a substantial economic burden, with global health expenditure estimated in the hundreds of billions of US dollars annually (Lippi and Sanchis-Gomar, 2020).

In the UK, around 670,000 people in England have a GP-recorded diagnosis of heart failure

(British Heart Foundation [BHF], 2025a), and the total number of people living with the condition across the UK has been estimated at over 900,000 (Health Education England, 2023). Population-based data from the Clinical Practice Research Datalink show that the absolute number of prevalent UK cases rose by 23% between 2002 and 2014, driven largely by an ageing population with increasing multimorbidity (Conrad et al., 2018). In Wales specifically, heart failure affects an estimated 31,000 people, alongside a much larger, often undiagnosed, population (Institute of Welsh Affairs, 2016), and cardiovascular disease as a whole is responsible for around one in four deaths in Wales (Welsh Government, 2025).

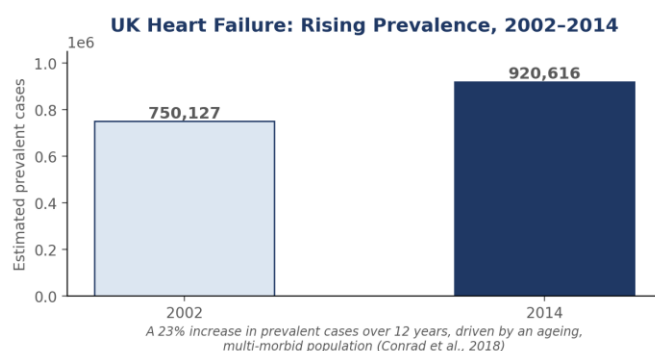


Figure 1. Growth in UK heart failure prevalence, 2002–2014 (Conrad et al., 2018).

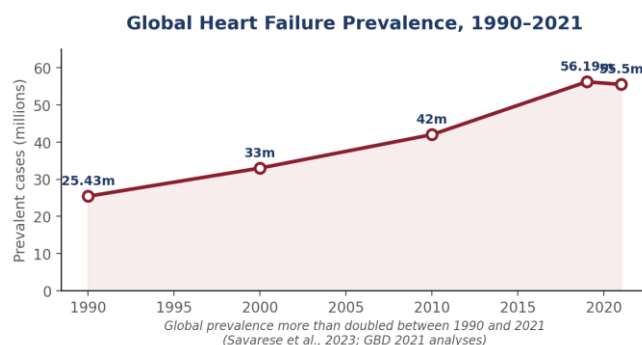


Figure 2. Global heart failure prevalence, 1990–2021 (Savarese et al., 2023).

Prognosis has improved but remains serious: UK cohort data show one-year survival after

diagnosis rising from 74.2% in 2000 to 80.8% by 2016, yet five-year survival is still below 50% (Taylor et al., 2019). Importantly, socioeconomic deprivation is strongly associated with both a higher incidence of heart failure and an earlier age of onset, highlighting heart failure as a condition with a significant, and partly preventable, health-inequalities dimension (Conrad et al., 2018).

4. Risk Factors and Aetiology

In the UK and other high-income countries, coronary artery disease and hypertension are the two leading causes of heart failure (McDonagh et al., 2021). Additional major risk factors include atrial fibrillation and other arrhythmias, valvular heart disease, diabetes mellitus, obesity, chronic kidney disease, excessive alcohol intake and smoking (Behnouch et al., 2023). Left ventricular hypertrophy secondary to poorly controlled hypertension is a well-recognised precursor to both reduced and preserved ejection fraction heart failure (Wang et al., 2025).

Age is the single strongest non-modifiable risk factor: the mean age at first presentation in UK cohorts is around 77 years, and prevalence rises steeply from the seventh decade of life onward (Conrad et al., 2018). However, many of the underlying drivers — hypertension, obesity, diabetes and smoking — are modifiable, meaning that a substantial proportion of heart failure is, in principle, preventable through earlier detection and treatment of these upstream conditions (Public Health Wales, 2025).

Risk Factors and Aetiology of Heart Failure

Non-Modifiable Risk Factors	Modifiable Risk Factors
Age (mean onset ~77 yrs)	Hypertension
Sex	Coronary artery disease
Genetic / inherited cardiomyopathy	Diabetes mellitus
Prior myocardial infarction	Obesity

In UK/high-income countries, coronary artery disease and hypertension are the leading causes (McDonagh et al., 2021; Behnouch et al., 2023)

Figure 3. Modifiable and non-modifiable risk factors for heart failure.

5. Impact of Heart Failure on Individuals and Families

5.1 Physical impact

Breathlessness, fatigue and reduced exercise tolerance dominate the physical experience of heart failure. In a large US qualitative study, the most commonly reported symptoms were shortness of breath (81.3% of patients), fatigue (76.6%), leg and ankle swelling (57.8%) and disturbed sleep (50.0%), with many patients also reporting difficulty walking and climbing stairs (McHorney et al., 2021). These physical limitations frequently restrict activities of daily living, employment and independence.

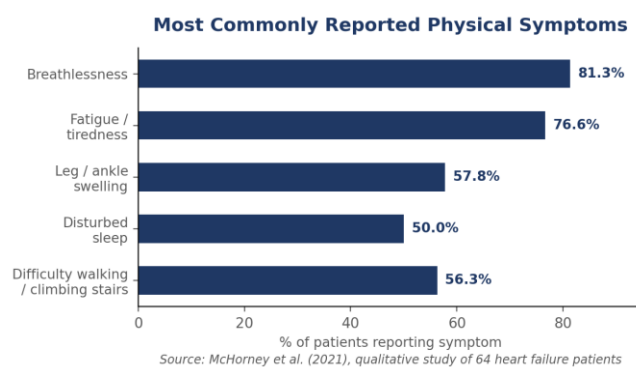


Figure 4. Most commonly reported physical symptoms (McHorney et al., 2021).

5.2 Psychological impact

Heart failure carries a heavy psychological burden. Systematic evidence indicates that anxiety affects roughly 20–50% of patients and depression 20–45%, considerably higher than in the general population (Anxiety and Depression in Heart Failure: An Updated Review, 2023, cited in ScienceDirect). Fear of dying, sadness and hopelessness are commonly reported alongside the physical symptoms (McHorney et al., 2021), and psychological distress is itself associated with poorer self-care, more frequent hospitalisation and increased mortality (International Journal of Mental Health Systems, 2021).

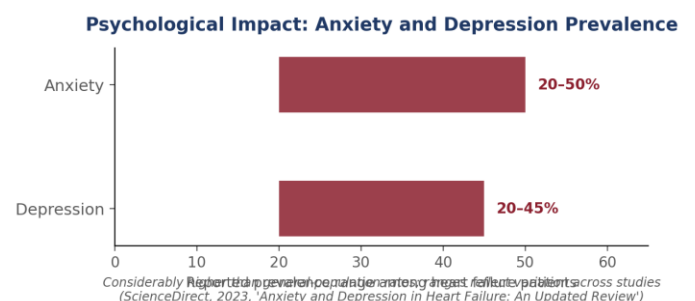


Figure 5. Reported prevalence ranges of anxiety and depression in heart failure.

5.3 Social impact

Socially, patients frequently describe reduced participation in family and social life, changes to diet and routine, and, for some, early retirement or reduced working hours (McHorney et al., 2021). The unpredictable trajectory of heart failure — periods of relative stability punctuated by acute decompensation — adds a layer of uncertainty that can further erode social confidence and community participation.

5.4 Wider implications for families and carers

The majority of day-to-day heart failure care is delivered not by health professionals but by family caregivers, usually a spouse of similar age (Sanders and Newman, 2022, cited in ScienceDirect). Caregivers report significant stress, disrupted sleep, social and emotional isolation, and, for some, a need to reduce paid work (McHorney et al., 2021). Qualitative research with nurses confirms that family caregivers frequently under-report their own burden in front of the person they care for, meaning their needs can go unrecognised by services (Registered Nurses' Perceptions about the Situation of Family Caregivers, 2016, cited in PLOS One). This 'invisible' caring role reinforces the case for family-inclusive assessment and support within heart failure services, rather than a sole focus on the patient.

6. Evidence-Based Treatment in the NHS

NICE guideline NG106 sets out the evidence-based pathway for diagnosing and managing chronic heart failure in adults across the UK (NICE, 2025). Diagnosis typically combines symptom assessment, natriuretic peptide (NT-proBNP) blood testing and echocardiography, with urgency of referral for specialist assessment determined by the NT-proBNP level (NICE, 2025).

6.1 Pharmacological treatment

For HFrEF, NICE and the European Society of Cardiology recommend early initiation of the so-called 'four pillars' of prognostic therapy: an ACE inhibitor or angiotensin receptor–neprilysin

inhibitor, a beta-blocker, a mineralocorticoid receptor antagonist, and a sodium-glucose co-transporter-2 (SGLT2) inhibitor, alongside loop diuretics for symptom control (NICE, 2025; McDonagh et al., 2021). Recent updates to NG106 extend SGLT2 inhibitor use to people with mildly reduced and preserved ejection fraction, reflecting new trial evidence (NICE, 2025).

The 'Four Pillars' of HFrEF Pharmacological Treatment

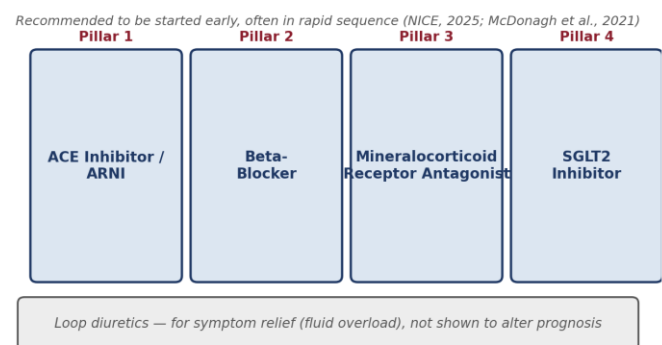


Figure 6. The 'four pillars' of HFrEF pharmacological treatment (NICE, 2025; McDonagh et al., 2021).

6.2 Device therapy and interventional procedures

Selected patients with HFrEF benefit from implantable cardioverter defibrillators (ICDs) to reduce the risk of sudden cardiac death, or cardiac resynchronisation therapy (CRT) to improve cardiac synchrony and symptoms (McDonagh et al., 2021).

6.3 Cardiac rehabilitation and self-management support

Exercise-based cardiac rehabilitation is strongly evidenced. A 2023 Cochrane systematic review of 60 randomised trials involving 8,728 patients found high-certainty evidence that exercise-based cardiac rehabilitation, whether centre-

based, home-based or hybrid, reduces hospitalisation risk and produces clinically meaningful improvements in health-related quality of life (Molloy et al., 2023). Despite this, national NHS workforce data show that only around one third of eligible heart failure patients are currently referred to rehabilitation, indicating a substantial implementation gap (Health Education England, 2023).

6.4 Palliative and supportive care

NG106 also covers palliative care as an integral part of the heart failure pathway rather than a service reserved for the final days of life (NICE, 2025); this is discussed further in Section 9.

7. Theoretical Models and Frameworks

Two complementary frameworks are widely used to improve outcomes for people with long-term conditions such as heart failure: one system-level UK model, and one internationally developed, individual-level model.

7.1 UK model: The House of Care

Developed by the King's Fund and adopted widely across NHS primary care, the House of Care model reorganises local services around collaborative care and support planning rather than single-disease clinics (Coulter, Roberts and Dixon, 2013). It is depicted as a house with four interdependent 'walls': engaged, informed patients; healthcare professionals committed to partnership working; organisational and clinical processes that support this; and commissioning that responsibly resources it — all resting on the

'foundation' of responsive commissioning (Coulter, Roberts and Dixon, 2013). Applied to heart failure, the model shifts care from a reactive, hospital-based response to decompensation toward proactive, planned, person-centred review, and has been evaluated specifically within cardiovascular services in England (British Heart Foundation, 2018).

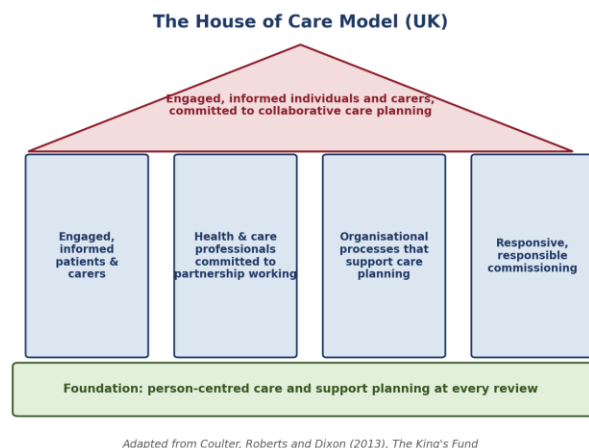


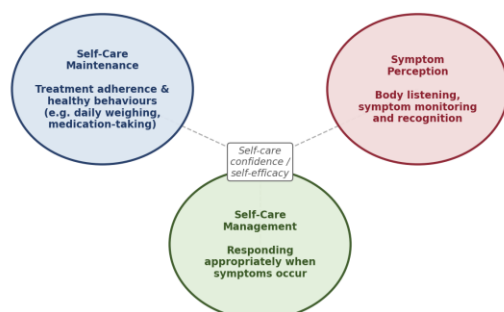
Figure 7. The House of Care model (adapted from Coulter, Roberts and Dixon, 2013).

7.2 International model: The Situation-Specific Theory of Heart Failure Self-Care

Developed in the United States by Riegel and colleagues, and now used internationally including in UK nursing research, this middle-range theory conceptualises heart failure self-care as a naturalistic decision-making process comprising three linked elements: self-care maintenance (treatment adherence and healthy behaviours, such as medication-taking and daily weighing), symptom perception (noticing and interpreting bodily changes) and self-care management (responding appropriately when symptoms occur) (Riegel, Dickson and Faulkner, 2016; Riegel, Dickson and Vellone, 2022). The

theory is influential because it explicitly incorporates the person's own knowledge, experience, confidence (self-efficacy) and social context, rather than treating self-management purely as compliance with clinical instructions (Riegel, Dickson and Vellone, 2022). Both models converge on the same underlying principle: sustainable improvement in heart failure outcomes depends on genuine partnership between an informed, supported individual and a proactive, coordinated service.

Situation-Specific Theory of Heart Failure Self-Care (International Model)



Adapted from Riegel, Dickson and Vellone (2022)

Figure 8. The three linked processes of heart failure self-care (adapted from Riegel, Dickson and Vellone, 2022).

8. Local and National Political Agendas

In England, the NHS Long Term Plan (2019) identifies cardiovascular disease as "the single biggest condition where lives can be saved by the NHS" over the following decade, with an ambition to prevent 150,000 heart attacks, strokes and cases of dementia by improving detection and treatment of hypertension, high cholesterol and atrial fibrillation (NHS England, 2019). Within this programme, NHS England has since launched a dedicated national heart failure improvement programme, projected to prevent hundreds of premature deaths and reduce

hospital bed-days by better supporting earlier diagnosis and access to rehabilitation (Health Innovation Network, 2025).

In Wales, the policy landscape has moved from the 2017 Heart Conditions Delivery Plan to the current Quality Statement for Heart Conditions, which sets out Welsh Government expectations for health boards and NHS trusts, including compliance with NICE guidance, national cardiac audit participation and equitable access to diagnostics (Welsh Government, 2025). This sits alongside Public Health Wales's Cardiovascular Disease Prevention Plan for Wales, an 'ABCD Plus' approach targeting blood pressure, cholesterol, diabetes risk and smoking to reduce the future burden of heart failure, particularly in the most deprived communities (Public Health Wales, 2025). Third-sector organisations such as British Heart Foundation Cymru continue to campaign for sustained political commitment, highlighting that variation in access to cardiac services — sometimes described as a 'postcode lottery' — remains a live political and clinical issue in Wales (British Heart Foundation Cymru, 2021).

Locally, individual health boards and integrated care systems are responsible for translating these national ambitions into service delivery, including community heart failure nursing teams, rapid-access diagnostic clinics and cardiac rehabilitation provision, in line with National Institute for Cardiovascular Outcomes Research (NICOR) audit standards (Welsh Government, 2025).

9. Recommendations for Person-Centred Care, Self-Management and End of Life Care

9.1 Person-centred care

Care should be organised around collaborative care and support planning, as described in the House of Care model, rather than a standardised, disease-only pathway (Coulter, Roberts and Dixon, 2013). In practice, this means giving people time and relevant information before consultations, agreeing goals jointly, and reviewing these regularly rather than only when the person is acutely unwell.

9.2 Supporting self-management

- Structured education on symptom recognition (breathlessness, weight gain, swelling) using the principles of the situation-specific theory of self-care, so people know when and how to act (Riegel, Dickson and Vellone, 2022).
- Routine referral to exercise-based cardiac rehabilitation, given the strong evidence for reduced hospitalisation and improved quality of life (Molloy et al., 2023).
- Involving family caregivers directly in education and support, recognising their central but often 'invisible' role (McHorney et al., 2021).
- Proactive screening for anxiety and depression, given prevalence rates several times higher than the general population (International Journal of Mental Health Systems, 2021).

9.3 End of life and palliative care

Because heart failure follows an unpredictable trajectory of decline punctuated by acute crises, palliative care is frequently introduced too late, or not at all (Chester et al., 2021). International heart failure societies now recommend a symptom-triggered, rather than purely prognosis-triggered, approach to palliative referral, so that people with significant symptom burden are supported regardless of predicted survival time (Palliative Approach for Heart Failure End-of-Life Care, 2018, cited in PMC).

Advance care planning (ACP) — voluntary, ongoing conversations about a person's future wishes — is strongly recommended, since evidence associates ACP with improved quality of life and reduced psychological distress in surviving relatives (Effect of Advance Care Planning on Heart Failure, 2020, cited in PMC). However, qualitative research with UK primary care professionals shows that stigma around the word 'palliative', uncertainty about whose role ACP is, and limited training remain significant barriers to these conversations happening early enough (Implementing Advance Care Planning in Heart Failure, 2021, cited in PMC). Embedding basic ACP training within pre-registration nursing and medical education, and normalising ACP as part of routine heart failure review rather than a marker of imminent death, are recommended as practical steps toward earlier, better-quality end of life conversations.

10. Conclusion

Heart failure is a common, serious and growing long-term condition that affects the whole person — physically, psychologically and socially — as well as their family. UK policy in both England and Wales increasingly recognises cardiovascular disease, including heart failure, as a priority for prevention, earlier diagnosis and person-centred management. Combining a system-level approach such as the House of Care with an individual-level understanding of self-care, alongside evidence-based pharmacological, rehabilitative and palliative care, offers the most promising route to improving both the length and the quality of life of people living with heart failure and those who care for them.

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(Harvard – Cite Them Right style)

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