

Spotlight on **Worsening heart failure**



The Heart Failure Policy Network is an independent, multidisciplinary platform made possible with financial support from Bayer AG, AstraZeneca, Vifor Pharma and Boehringer Ingelheim. The content produced by the Network is not biased towards any specific treatment or therapy. All outputs are guided and endorsed by the Network's members, who have full editorial control. All members provide their time for free.

Authorship and acknowledgements

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Considerable thanks and acknowledgement are due to all members of the Project Advisory Group for their continued input throughout the development of the report:

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The HFPN would also like to thank the following experts for sharing their knowledge in interviews:

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Executive summary

Early detection of worsening heart failure (HF) offers a window of opportunity to prevent hospitalisations. Worsening HF is the deterioration of HF signs and symptoms, which can occur over a long period of time outside of hospital, before admission is needed.^{1 2} Along with early detection, improved management of worsening HF in outpatient settings could help prevent hospitalisations.¹

Worsening HF impacts people's quality of life and places a substantial burden on society. It affects physical, emotional and social aspects of a person's life.³ It is a major cause of hospitalisation in the European Union, placing a significant economic burden on health systems.⁴⁻⁶

In clinical practice, worsening HF is often underdiagnosed. Specific markers of worsening HF have not been established, leading to inconsistent and frequently delayed diagnosis.⁷⁻⁹ Changes in some markers, such as weight gain, may not be detected until it is too late to prevent hospitalisation.¹⁰

Barriers to effective, evidence-based treatment of worsening HF include insufficient adherence to therapeutic recommendations and lack of reimbursement. Poor adherence is a major factor in hospitalisation owing to a severe episode of worsening HF.¹¹ In some countries, pharmacological and device-based therapies that can relieve symptoms are not reimbursed.¹⁰

Organisational barriers in hospital and follow-up care hinder improvement of outcomes for people who experience severe episodes of worsening HF. Residual fluid retention may be under-recognised and undertreated, despite being associated with higher risk of rehospitalisation and mortality.¹² Prompt and efficient follow-up care after hospital discharge is lacking, despite its importance in improving outcomes for people at risk of severe episodes of worsening HF.¹³⁻¹⁵

A shift towards health maintenance and telemonitoring can keep people with HF well and out of hospital. Maintaining the overall health of people with HF and detecting deterioration of signs and symptoms early are essential for timely treatment of worsening HF. Care pathways that are supported by telemonitoring tools, such as implanted devices, play a key role in early detection and management.¹⁶⁻²⁰

Outpatient care for worsening HF can improve outcomes and reduce costs. Monitoring and treating worsening HF in outpatient settings can increase people's quality of life, reduce hospitalisations and alleviate the burden of the syndrome on health systems.^{1 2 21-23}

HF specialist nurses are essential to provide person-centred care and bridge the gap between outpatient and inpatient settings. HF specialist nurses are well-positioned to offer tailored care, improve patient education, and monitor and treat people with HF in outpatient settings.^{10 23-26}

Key actions to improve detection and management of worsening HF

<p>1. Increase awareness and recognition of worsening HF</p>	<p>Worsening HF should be recognised as an important component in the clinical course of HF, the effective management of which could help prevent hospitalisations and improve outcomes.</p>
<p>2. Focus on health maintenance for people living with HF</p>	<p>HF care models should shift from the current approach of responding to worsening HF episodes only when hospital admission is needed, towards optimising health and quality of life.</p>
<p>3. Encourage the management of worsening HF outside of hospital</p>	<p>Decision-makers should facilitate the transition of care to an outpatient setting for worsening HF, to improve long-term management and provide person-centred care.</p>
<p>4. Improve access to advanced diagnostic tools and guideline-recommended treatments</p>	<p>It is crucial that people with HF have adequate access to advances in monitoring, diagnostic tools and treatment.</p>
<p>5. Accredite and fund HF specialist nurses</p>	<p>Adequate training, accreditation and resourcing of HF specialist nurses are vital to optimise their essential role in facilitating communication across care settings and person-centred care.</p>

What is worsening heart failure?

Early detection of worsening heart failure offers a window of opportunity to prevent hospitalisations

Worsening heart failure (HF) is the deterioration of HF signs and symptoms after a period of clinical stability.^{1 27} For example, worsening HF can involve breathlessness, fatigue, and swelling of the limbs or abdomen due to fluid retention.¹⁵ If left untreated, symptoms such as fluid retention can deteriorate, leading to a severe episode of worsening HF, where people require intensified treatment such as intravenous diuretic therapy.^{7 15 28-31} Deterioration in signs and symptoms may occur for weeks before hospitalisation is needed.^{1 2} Early detection and improved management of worsening HF in primary care and outpatient settings could help prevent severe HF events and keep people out of hospital (*Figure 1*).¹

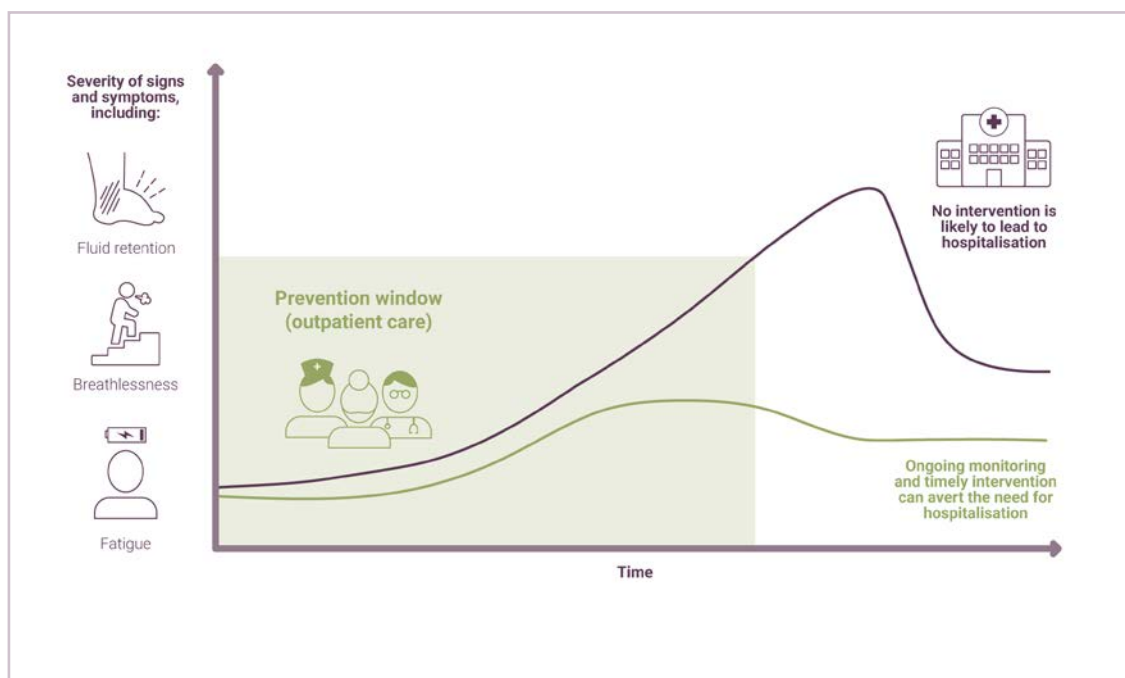
HF is a chronic syndrome and major cause of hospitalisations

HF is a complex clinical syndrome where the heart becomes too weak or stiff to pump sufficient blood to meet the body's needs.¹⁵ It is a chronic condition affecting more than 15 million people and is a major cause of preventable hospitalisations in Europe.^{32 33} People with HF may experience acute episodes – the rapid or gradual onset of signs and symptoms requiring urgent medical intervention, such as a hospital admission.¹⁵ This can be classified as a new case if the person does not have prior history of HF, or as acute decompensated HF if the person has already been diagnosed with HF.

Worsening HF often leads to acute HF

It is estimated that one in six people living with HF will develop worsening HF within 18 months after diagnosis.³⁴ The key feature of worsening HF is a deterioration of signs and symptoms that indicate cardiac dysfunction, known as cardiac decompensation.³⁵ Worsening HF often leads to acute HF (a severe episode of worsening HF), but also includes deterioration of signs and symptoms that do not require hospitalisation and can be treated in outpatient settings.^{1 35} In fact, some experts have suggested that acute HF episodes may be the culmination of worsening HF that has gone undetected.^{8 36}

Figure 1. The window to prevent hospitalisations for worsening HF



There is increasing recognition of the need to treat worsening HF

Over the past decade, healthcare professionals have started recognising worsening HF as an important clinical event in the lives of people with the syndrome.^{8 37} More clinical trials are including worsening HF as a key outcome measure to assess the benefit of treatments. There are also efforts to treat the deterioration of symptoms in outpatient settings rather than hospital.^{1 2 38} However, a lack of clarity regarding the diagnostic criteria for worsening HF has slowed these efforts.^{8 37} Establishing a specific measurement and time frame for the deterioration of signs and symptoms will be essential to facilitate diagnosis and improve treatment.^{10 39}

Treatment for worsening HF symptoms is available

During an episode of worsening HF, the heart cannot pump enough oxygen around the body.⁴⁰ To compensate, the body produces hormones to improve the heart's ability to contract. However, this may result in impaired kidney function, which in turn leads to fluid retention and swelling.⁴¹ Intravenous diuretics are the treatment most widely used for worsening HF during hospitalisation, while other medications such as inotropes and vasodilators are used to treat a small fraction of the most severely affected patients.^{28 42} Diuretics relieve fluid retention by reducing the volume of circulating blood. While an appropriate dose of diuretics alleviates fluid retention, high doses may induce dehydration and worsening kidney function.⁴¹

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The impact of worsening heart failure episodes

Worsening HF is a major driver of hospitalisations and death

HF is a leading cause of preventable hospitalisations for chronic conditions in the European Union (EU),⁴ and up to 70% of HF-related hospitalisations are a result of worsening HF.⁴² People with worsening HF stay in hospital for longer and have a high rate of readmission, leading to recurrent hospitalisations.^{9 31 43-45} Better management of worsening HF in outpatient settings could reduce hospital admissions.¹ It is estimated that each subsequent HF hospitalisation significantly increases the risk of death for people with worsening HF.^{29 46 47} One in five people will die within two years of a severe episode of worsening HF.³⁴

Care for worsening HF is resource intensive

Frequent hospitalisations are a major contributor to the costs of HF care in the EU.^{5 6} US studies show that the cost of care following a severe episode of worsening HF can be three times higher than for those people whose HF is stable.⁴⁸ Data specific to the care costs of worsening HF in Europe are scarce. Research in European countries is urgently needed to gain a better understanding of the contribution of worsening HF to the economic burden of the syndrome.

Worsening HF reduces quality of life and wellbeing

The symptoms of worsening HF and need for frequent hospitalisations can affect a person's quality of life physically, emotionally and socially.³ The impact of HF is substantial, even when compared with that of other chronic conditions.⁴⁹ Fatigue, a key symptom of worsening HF, is associated with depression and may increase isolation, affect relationships, and lead to loss of independence and poorer work performance.⁵⁰ Mental health issues such as depression, anxiety and panic disorders are common in people with HF.⁵¹⁻⁵³ Decreased quality of life can also negatively affect other outcomes among people with HF, increasing the risk of readmission and death.⁵⁴

'It's quite frightening when you have a cardiogenic shock, but I recovered from that. What's interesting is that I'm still very conscious of my heart. I start thinking: is this going to get worse? Am I more at risk? Is my quality of life going to be seriously affected? How much can I control this with lifestyle and treatment?'

Steven Macari, HF patient

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Challenges in detection and management of worsening heart failure

'We must provide guidance on how to diagnose and manage worsening HF to healthcare professionals. It is very important to have diagnostic criteria and tools to guide treatment in primary care.'

Dr Marta Kałużna-Oleksy, cardiologist

Lack of awareness and of clear diagnostic criteria for worsening HF hamper early detection

It can be difficult to diagnose worsening HF owing to the overlap in symptoms with other conditions and comorbidities.^{10 39} Worsening HF does not have clear, consensus-based diagnostic criteria that can be used consistently in clinical practice.⁷⁻⁹ Such variation leads to a missed opportunity to detect worsening HF and intervene early.^{7 30 31 36 37 55}

Detection of worsening HF currently relies on indirect measurements

A person with worsening HF may experience weight gain owing to fluid retention for weeks prior to hospital admission.⁵⁶⁻⁵⁸ The European Society of Cardiology guidelines recommend daily weight measurement for all people living with HF, to help monitor symptoms and adjust treatment.¹⁵ However, weight gain alone is not sensitive or specific enough to detect worsening HF.^{56 57 59} Other measurements that require regular monitoring for all people with HF include heart rate and blood pressure.¹⁵ These markers allow non-invasive detection of worsening HF, and can reduce HF hospitalisations and mortality.^{60 61} But, too often, changes in these biomarkers are not detected until it is too late to prevent hospitalisation.¹⁰

Lack of adherence to HF treatment is common

A recent study across 10 European countries showed that 50% of cases of worsening HF in primary care were caused by problems with adherence to medication and dietary recommendations.¹¹ Non-adherence to medication is among the most common factors leading to hospitalisation or death following a severe episode of worsening HF, although self-reporting may have skewed some studies.^{11 62 63} Lack of adherence to medication may be a result of intolerability, side effects, or a lack of understanding owing to cultural barriers or comorbidities such as dementia.^{25 26} This reinforces the case for early intervention to prevent further deterioration, and for further research to understand and support people to better adhere to treatment and dietary recommendations.



Access to optimal treatment to reduce symptoms of worsening HF is limited

Experts have highlighted that optimising medication is essential to prevent severe episodes of worsening HF.¹⁰ Numerous pharmacological and device-based therapies are available, but improved access is needed in some countries. Access to medication is often subject to reimbursement negotiations in national and regional health systems. In Poland, for example, the lack of reimbursement means healthcare professionals may be unable to provide guideline-recommended treatment in some cases.³⁹ Across Europe, even where medications are available, prescriptions often do not reach target doses recommended by international guidelines.⁶⁴

'We have an opportunity to prevent worsening HF by identifying patients who are undertreated and optimising their treatment. We have numerous life-saving therapies, but we need reimbursement for and easy access to these pharmacological and device-based treatments.'

Dr Pieter Martens, cardiologist

Residual symptoms of worsening HF may be under-recognised in hospital care

The main goal of therapies following a severe episode of worsening HF is the reduction of fluid retention.³⁶ Despite this, people with worsening HF are often discharged from hospital with residual fluid retention.²⁸ Residual fluid retention is under-recognised and undertreated, despite being strongly associated with a higher risk of hospital readmission and mortality.¹² Most people with HF have residual fluid retention at or shortly after discharge from hospital. The most widely used treatment to relieve fluid retention due to worsening HF is diuretics.⁶⁵ However, high doses of diuretics may lead to kidney dysfunction, which can in turn increase fluid retention.⁶⁶ This link between diuretics and kidney function is the most common reason for residual fluid retention remaining unresolved at the point of discharge. Persistent fluid retention can also be the result of diuretic resistance (a lack of diuretic response despite higher doses of diuretics),³⁶ which is associated with an increased risk of mortality.⁶⁷ Further research is needed to determine objective assessment and optimal fluid status of people with HF before being discharged.



Worsening HF often goes undetected owing to a lack of follow-up care after hospitalisation

Effective long-term follow-up is vital to detect worsening HF, improve management and reduce the risk of future readmission. More than one third of people diagnosed with HF following hospitalisation are not followed up after discharge in primary care, which leads to less frequent treatment optimisation and increased mortality.¹³ This is despite evidence that structured follow-up in outpatient care after discharge is essential to improve outcomes of people at risk of worsening HF.^{14 15} Following hospitalisation, progressive worsening of symptoms remains an important challenge in the management of chronic HF.³⁴



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Best practice in detection and management of worsening heart failure

Patient involvement and a proactive care model can keep people out of hospital

It is essential to shift from a model of reactive care for worsening HF, responding to emergency severe episodes, to maintenance of the best possible health.^{15 68} Improved care for people living with HF can lead to the prevention of worsening HF. Person-centred care and patient involvement play a key role in improving outcomes and quality of life.⁶⁹ People with HF highlight that being an active participant in the management of their condition is an important way to regain control and improve their psychological wellbeing.²⁶ Keeping a healthy lifestyle and detecting changes in signs and symptoms early can prevent deterioration.

Telemonitoring can enable early detection and intervention


It is important to monitor people at high risk of severe episodes of worsening HF.¹⁰ Devices linked to algorithm-based diagnostic tools can detect early signs of worsening HF up to two months in advance of severe exacerbation, providing sufficient time to intervene.¹⁶⁻²⁰ Studies have found that implanted devices can reduce hospitalisations and healthcare costs, and improve outcomes and quality of life.⁷⁰⁻⁷² People with HF report that non-invasive telemonitoring tools can also support them to monitor their symptoms.²⁶

'It can be really worrying when you notice a change in symptoms; for example, the heart beating faster. Telemonitoring tools can help you check your symptoms at home, understand them better and make lifestyle choices accordingly.'

Penilla Gunther, HF advocate

Outpatient care for worsening HF can improve outcomes and reduce costs

Outpatient settings, such as cardiology or HF units, provide an opportunity to monitor and treat worsening HF.^{1 2 21-23} This can increase people's quality of life while reducing hospitalisations and healthcare costs. For example, treating worsening HF episodes with intravenous diuretics in an outpatient setting is safe and can improve outcomes, preventing hospitalisation and facilitating a person-centred approach.^{22 23} US studies have found that switching to outpatient treatment of worsening HF can alleviate the burden of hospitalisations on health systems and could achieve cost savings of up to USD \$667.5 million, even when only 10% of hospital admissions are shifted to the outpatient setting.⁷³



'HF nurses are not recognised or rewarded enough. They have a privileged relationship with patients; they treat them on a human level, listening and understanding to where the patient is coming from. They don't look at the illness, but at the person who is in front of them.'

Steven Macari, HF patient

HF specialist nurses provide person-centred care and can bridge the gap between care settings

Recognising and resourcing the role of HF specialist nurses is vital to improve management of worsening HF. HF nurses are often responsible for monitoring signs and symptoms of worsening HF, identifying deterioration and providing treatment in outpatient settings.^{23 74 75} Experts have highlighted that HF specialist nurses are also well equipped to ensure collaboration between hospital and outpatient settings.¹⁰ HF nurses often have a closer relationship with patients than other healthcare professionals and can provide tailored, person-centred care and improve patient education.²⁴⁻²⁶ Experts have also suggested that the HF care workforce should be further expanded with allied health professionals to promote patient education.³⁹

Effective hospital discharge protocols can improve outcomes

Residual fluid retention at hospital discharge is common among people with HF, despite its association with increased risk of hospital readmission and death.^{12 28} There is accumulating evidence that prioritising the relief of fluid retention is essential to reduce risk of readmission and mortality.⁷⁶⁻⁷⁸ Experts have suggested that measuring diuretic response to ensure treatment effectiveness, developing clear discharge notes and implementing follow-up plans could improve outcomes.^{10 65} Follow-up in primary care after a hospitalisation has also been shown to reduce subsequent hospital visits and improve outcomes.¹⁴



Case study

Keeping people with HF stable via a virtual platform^{79 80}

In the Netherlands, an eHealth platform for disease management (e-Vita) and the website heartfailurematters.org promoted monitoring of worsening HF and improved self-care in the short term. HF specialist nurses educated people living with HF and their carers on the use of the e-Vita platform and how to record body weight, blood pressure and heart rate every day. The HF nurses adjusted thresholds in collaboration with patients to maintain optimal health while avoiding unnecessary alerts. If thresholds were crossed, the platform sent an alert to an HF nurse, who called the patient to ask about their symptoms and either adjust treatment accordingly or recommend a visit to an outpatient clinic, general practice or hospital.

Case study

Treating worsening HF with an ambulatory service²³

In England, an HF service was introduced to provide intravenous diuretics to people with a worsening HF episode. Risk stratification ensured that those with lower risk received the ambulatory service at home, while people considered high risk were directed to the day centre. The care team included cardiologists and HF specialist nurses. The home visit allowed monitoring of signs and symptoms and the data were shared with the hospital, allowing the continuation, escalation or discontinuation of intravenous diuretics according to the data received. Most of the worsening HF episodes were managed by the ambulatory service without complications. Only 20% of people required hospital admission to receive higher doses of treatment. Importantly, the service achieved a significant reduction in mortality compared with hospital admission.

Case study

Improving medication adherence with pharmacy-based care⁸¹

In Germany, an intervention in primary care increased medication adherence among people with HF to 80%. The intervention included the development of a medication plan and provision of appropriate medication. During biweekly visits to the pharmacy, the care team monitored symptoms and adjusted medication if appropriate. Importantly, people with HF reported improved quality of life as a result of the intervention.

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The way forward

Timely detection of and effective intervention for worsening HF is an important target to improve outcomes and prevent severe episodes

Worsening HF is the main cause of HF-related hospitalisation and is linked to poorer outcomes for people living with HF.^{9 31 43 62 82 83} Timely detection and appropriate management of worsening HF have the potential to reduce hospitalisations and mortality. However, worsening HF is poorly defined, diagnostic tools are not readily available and guideline recommendations regarding treatment are often not followed. These are missed opportunities to improve the lives of people with HF, prevent hospitalisations and alleviate the burden of the syndrome on health systems across Europe.

Concerted action is required to improve the detection and management of worsening HF

We propose actions to improve detection of worsening HF and intervene early to reduce hospitalisations and mortality, and increase quality of life for people with HF.

1. Increase awareness and recognition of worsening HF

Worsening HF should be recognised as an important component in the clinical course of HF, the effective management of which could help prevent hospitalisations and improve outcomes. Professional societies should establish consensus- and evidence-based biomarker measurements to facilitate diagnosis across care settings. People living with HF and their carers should be supported to recognise the signs and symptoms of worsening HF and request medical intervention when needed. This will be essential to ensure timely intervention and appropriate management of worsening HF.

2. Focus on health maintenance for people living with HF

HF care models should shift away from the current reactive approach, responding to episodes of worsening HF only when hospital admission is needed, towards proactively optimising health and quality of life. Telemonitoring tools can empower people with HF to play a more active role, improving self-care and psychological wellbeing.^{25 26 84}

3. Encourage the management of worsening HF outside of hospital

Decision-makers should facilitate the shift towards outpatient care for episodes of worsening HF, to improve long-term management, slow down disease progression and provide a more person-centred approach. Evidence and expert opinion suggest that outpatient care for people with worsening HF is safe, effective in improving outcomes, and results in reduced hospitalisations, thus alleviating the personal and economic burden of HF.^{1 2 21-23} Expert consensus, clear guidelines and implementation policies are required to make this shift a reality.



4. Improve access to advanced diagnostic tools and guideline-recommended treatments

In recent years, there have been significant improvements in monitoring and diagnostic tools, such as implanted devices, as well as treatments to improve the detection and management of worsening HF.^{10 85 86} It is crucial that people with HF have adequate access to these options.^{10 39} Further research is needed to develop diagnostic tools and interventions for worsening HF and ensure they lead to improved outcomes.

5. Accredite and fund HF specialist nurses

Despite the crucial role HF specialist nurses play in improving care quality and outcomes for people with worsening HF, their role remains underfunded and lacks accreditation across Europe.³³ HF nurses have the potential to assist people experiencing an episode of worsening HF and increase adherence by improving patient education, monitoring signs and symptoms, and providing optimised treatment in outpatient settings.^{23 24 74 75} In addition, HF nurses play an essential role in facilitating communication across care settings and the provision of person-centred care.^{10 25 26} It is therefore vital to provide adequate training, accreditation and resourcing for HF specialist nurses.³³

The time has come to recognise and improve the management of worsening HF

Achieving a shift in the model of care for worsening HF requires joint action by experts, healthcare professionals, patient advocates and policymakers. Worsening HF is too often seen as an inevitable decline, but the evidence shows it is an opportunity for action. If the HF community can unite behind a positive vision of early detection and intervention, we can reduce HF-related hospitalisations and mortality, and give hope to the millions of people living with HF across Europe.

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About the Heart Failure Policy Network

The Heart Failure Policy Network (HFPN) 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 unmet needs surrounding heart failure and its care. All members provide their time for free. All Network content is non-promotional and non-commercial. The Secretariat is provided by The Health Policy Partnership Ltd, an independent health policy consultancy based in London.

Please cite this report as: Heart Failure Policy Network. 2022. *Spotlight on worsening heart failure*. London: HFPN

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