Executive Summary

Cardiovascular disease (CVD) is the number one cause of death in Europe as well as in the European Union (EU), where it is responsible for 3.9 and 1.8 million deaths respectively every year. CVD mortality is falling in most European countries. However, declining death rates do not go hand in hand with declining morbidity. The number of CVD patients remains at a very high level; in the EU alone, almost 49 million people live with cardiovascular disease.

Within CVD, heart failure is a condition, which is common but neither widely known nor simple. The main causes of heart failure are coronary heart disease and high blood pressure.

Heart failure brings about dramatic changes in people’s lives. Normal activities such as taking the stairs, engaging in domestic chores such as cleaning, walking to the shops, or even putting on clothes become more and more difficult, the worse the condition becomes. Patients become increasingly isolated, unable to pursue hobbies or maintain social contacts. Additionally, for people of working age, these symptoms and disabilities can also affect ability to maintain employment, as well as productivity. As far as quality of life is concerned, a primary care-based cohort study with ten-year follow up in Scotland from 2017 came to the conclusion that people with heart failure have a lower quality of life than people with most forms of cancer.

In developed countries, the prevalence is 1-2% of the population; this means that more than 10 million people in the EU could be affected. The prevalence of heart failure is set to increase, due to an ageing population and occurrence of co-morbidity factors. In most westernised economies, heart failure is responsible for about 2% of all healthcare expenditure. A study from 2014 estimated the costs related to heart failure in the EU to be around €29 billion in one year.

Early diagnosis is key as is early initiation of appropriate treatment to relieve symptoms, prevent additional organ damage and improve prognosis.

EHN recommends:

1. to raise awareness of the symptoms of heart failure among the general public and those at risk
2. to improve the diagnosis of heart failure, through awareness-raising and better training of primary healthcare professionals leading to a swift referral to specialists
3. that patients receive tailored support from a specialised multi-disciplinary team, as appropriate, to treat heart failure as well as co-morbidities
4. that research should focus on finding treatments, especially for heart failure with preserved ejection fraction, which can help the heart muscle work efficiently again, repairing damage and/or reducing overload
5. to improve collection of data on heart failure across Europe and make them available in registries.

**Aim**

The aim of this paper is to raise awareness of heart failure as a major health burden throughout Europe.

This burden is felt heavily by those who live with heart failure, their families and carers. It is also a significant burden on healthcare systems and society as a whole.

To alleviate the burden, it is essential that sufficient investments are made in research, in raising awareness, and in improving the health system to allow early recognition and initiation of appropriate treatment that can improve prognosis and quality of life.

**Introduction**

Cardiovascular disease (CVD) is the number one cause of death in Europe as well as in the European Union (EU), where it is responsible for 3.9 and 1.8 million deaths respectively every year. CVD is also the leading cause of premature death (under 75 years) and in working age people (under 65 years) in Europe, accounting for 1.3 million deaths in people under the age of 75 and 667,000 in those under the age of 65. In contrast to Europe as a whole, in the EU CVD is the second largest cause of mortality in those under 75 years, resulting in more than 436,000 deaths, and in those under 65 years, resulting in 192,000 death.¹

Nevertheless, overall CVD mortality is falling in most European countries, including Central and Eastern Europe which, until the beginning of the 21st century, saw considerable increases. Despite this positive trend, declining death rates due to CVD sadly do not go hand in hand with declining morbidity. In other words, whilst fewer people die from CVD, the number of CVD patients remains at a very high level.² In 2015, there were more than 6 million new cases of CVD in the EU alone (more than 11 million in Europe). With almost 49 million people living with the disease in the EU, the absolute number of CVD cases rose by 32% among males and 26% among females from 1990 to 2015. This trend is linked to an increase in the total population, in particular, in older people.

Overall, CVD is estimated to cost the EU economy a total of €210 billion (2015 figures).³

Within CVD, heart failure is a condition, which is common but neither widely known nor simple. Heart failure occurs when the heart is either too weak to pump blood in sufficient amounts through the arteries (systolic heart failure or heart failure with reduced ejection fraction) or is lacking elasticity to fill with enough blood (diastolic heart failure or heart failure with preserved ejection fraction). As a result, vital organs such as brain, kidneys and muscles, do not receive enough oxygen and nutrients to function fully.

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1. What we know

**Causes of heart failure**

The main causes of heart failure are coronary heart disease, where the arteries around and within the heart narrow, due to the build-up of plaque (atherosclerosis), and consequently make the blood supply to the heart muscle more difficult, and high blood pressure (hypertension). Together, they account for around 70% of heart failure. Heart valve disease, abnormal heart rhythm, and heart defects at birth can also lead to heart failure. Other diseases or medical risk factors, such as diabetes, chronic obstructive pulmonary disease, chronic kidney disease, and raised cholesterol, as well as behavioural risk factors, such as poor diet, obesity, smoking, alcohol abuse, and a sedentary lifestyle also play an important role. A combination of the above make heart failure, and complications of heart failure, more likely.

**The symptoms**

Typical symptoms of heart failure include shortness of breath, fatigue, fluid retention and ankle swelling. Heart failure can also impact on a patient’s ability to sleep or impair his/her cognitive function. The condition is disabling and distressing and can have a major effect on the quality of life of patients and their families.

Heart failure usually starts gradually with non-specific/tenuous symptoms. For example: when going upstairs a person has to stop because of shortness of breath that has not occurred before; or water retention in the lower legs and/or ankles combined with a fatigue that has not been there before and cannot be explained by changed circumstances, such as warm weather.

If these symptoms occur, the person should immediately see his/her general practitioner. The earlier heart failure is diagnosed the better the chances for successful treatment. If the general practitioner has the slightest suspicion of heart failure (based on clinical history, signs/symptoms) and if s/he cannot rule out heart failure, i.e. on the basis of the results of a blood test and an electrocardiogram (ECG), s/he must refer his/her patient to a cardiologist for echocardiography immediately. As heart failure can be difficult to diagnose because many of its symptoms may be caused by several other conditions, such referral often does not happen. It is, therefore, very important that general practitioners are made aware of and are alert to the symptoms and their patients’ potential risk of heart failure as well as treatment options.

**Diagnosis**

An echocardiography (ultrasound) is the most common reliable means of assessing heart function including for diagnosing potential damage to the heart muscle (or parts of it), and possible defects of the heart valves. An ECG can point to enlargement of the ventricles or thickening of the heart muscle. An exercise test with ECG helps determine the heart’s ability to work when undertaking physical exercise. Sometimes, an X-ray is needed to show evidence of fluid in the lungs. Cardiovascular magnetic resonance imaging (CMR) is used to quantify ventricular function, assess valves, and potentially determine the cause of heart failure (for example, ischaemic, non-ischaemic or infiltrative). Cardiac CT is increasingly used to exclude coronary artery disease. In addition, the biomarker NT-proBNP can help to determine whether shortness of breath is a symptom of heart failure or primarily due to a non-cardiac cause. Cardiac catheterisation is used selectively for investigation of coronary artery disease and may be used to determine the functionality of the left and right ventricles (by measurement of pressures not only angiography), and for lung pressures (pulmonary vascular resistance calculation).

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Das schwache Herz, Diagnose und Therapie der Herzinsuffizienz heute. German Heart Foundation (2017)
The consequences

If not diagnosed in a timely fashion and treated with the appropriate therapy, heart failure might lead to further decline of the heart’s ability to pump. A heart failure patient might move from a stage where s/he only notices an impact when s/he is undertaking tough physical exercise to a stage where s/he is bed-ridden. If the disease is advanced, complications, such as deterioration of kidney function or arrhythmia, are likely to occur.

Treatment

The goal of current therapy is to stop or, at least, slow down the consequences of heart failure. The chances for success are greater the earlier the diagnosis is made. Therapy aims not only to increase life expectancy of heart failure patients, but also to help patients enjoy a good quality of life. As such, therapy includes four different approaches which are utilised depending on the time of the diagnosis and the severity of the disease:

1. finding and treating the underlying causes is crucial – e.g. control of hypertension, replacement of damaged heart valves
2. addressing the risk factors – exercise as therapy, supported by the necessary lifestyle changes, e.g. making adjustment to diet and stopping smoking
3. medication – the core of treatment is initiation of preventive medical treatment, e.g. Angiotensin Converting Enzyme (ACE) inhibitors or Angiotensin II Receptor Blockers (ARB), beta-blockers, diuretics and mineralcorticoid inhibitors for patients with heart failure with reduced ejection fraction. For patients with symptoms despite optimal medical treatment, treatment with sacubitril/valsartan instead of ACE/ARB is recommended. For patients with heart failure with preserved ejection fraction, no effective treatment is currently available and treatment is aimed at the underlying condition and symptom relief. Symptom relief and treatment of fluid retention is done with diuretic medication.
4. specific implantable devices such as pacemakers – CRT, cardiac resynchronisation therapy; ICD, implantable cardioverter defibrillator.

If all of above have been exhausted and the heart failure patient is at an advanced stage of the disease, a heart transplant might be necessary or implantation of a mechanical pump to assist the heart if transplantation is not an available option.

2. The burden on patients and their carers

Heart failure brings about dramatic changes in people’s lives. What used to be a normal part of a daily routine, such as taking the stairs, engaging in domestic chores such as cleaning, walking to the shops, or even putting on clothes become more and more difficult, the worse the condition becomes. Patients become increasingly isolated, unable to pursue hobbies or maintain social contacts. They also depend more and more on the help of carers, frequently family members, which can put a strain on relationships.

Additionally, for people of working age, these symptoms and disabilities can also affect ability to maintain employment, as well as productivity.

Physicians use the classification of the New York Heart Association (NYHA), which describes four different classes of heart failure, from class I (ordinary physical activity does not cause undue fatigue, palpitation, shortness of breath) to class IV (if any physical activity is undertaken, discomfort increases; may cause the patient to be bed-ridden). Depression and anxiety are recognised side effects of heart failure, with around 10% of patients in class II, and 40 to 70% in
classes III and IV suffering from them. Unsurprisingly, heart failure patients with depression find it generally more difficult to adhere to the therapy agreed with their physician compared to those not suffering from depression. This is because these patients often also have cognitive dysfunction, where they no-longer recognise symptoms or misinterpret them. In addition, memory loss is a frequent side effect. Therapy compliance should be encouraged/promoted in every patient but especially in those who suffer depression.

As far as quality of life is concerned, a primary care-based cohort study with ten-year follow up in Scotland from 2017 came to the conclusion that people with heart failure have a lower quality of life than people with most forms of cancer.

A healthier lifestyle, with more exercise, a healthy diet, low in salt and saturated fat, and with lots of fruits and vegetables, and no smoking, can have a positive impact on quality of life, especially in the earlier stages. However, patients often find it difficult to make those lifestyle changes and to continue with them in the long term.

Finally, adherence to medication is low. Therefore, it is absolutely critical that doctors make sure that their patients understand that, to increase their life expectancy and enjoy a good quality of life, they must adhere to their therapy, i.e. take their drugs according to the prescribed schedule and follow instructions regarding dietary changes and exercise.

3. The burden on society

We do not have prevalence figures for heart failure in Europe or in the EU. Several studies estimate that, in developed countries, the prevalence is 1–2% of the population, rising to over 10% among people aged over 70. In the EU, with a population of over 510 million people, this could mean that more than 10 million people live with heart failure. The 2008 ESC guidelines for the diagnosis and treatment of acute and chronic heart failure estimated that at least 15 million people in Europe are affected. The lifetime risk for individuals aged 55 years is 33% for men and 28% for women.

Heart failure is responsible in most westernised economies for about 2% of all healthcare expenditure. A study conducted by a research group at the International Centre for Circulatory Health at Imperial College London in 2012, estimated the costs related to heart failure in the EU (24 Member States) in one year to be US$ 33.14 billion (~€29 billion). The bulk of the costs are driven by frequent, prolonged and repeat hospitalisations. The EHN’s 2017 CVD statistics

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5 Das schwache Herz, Diagnose und Therapie der Herzinsuffizienz heute. German Heart Foundation (2017)
7 Ponikowski, P. et al. 2016 ESC guidelines for the diagnosis and treatment of acute and chronic heart failure. The Task Force for the diagnosis and treatment of acute and chronic heart failure of the European Society of Cardiology (ESC). Developed with the special contribution of the Heart Failure Association (HFA) of the ESC. *Eur Heart J* 37, 2129-2381 (2016)
8 Ponikowski, P. et al. 2016 ESC guidelines for the diagnosis and treatment of acute and chronic heart failure. The Task Force for the diagnosis and treatment of acute and chronic heart failure of the European Society of Cardiology (ESC). Developed with the special contribution of the Heart Failure Association (HFA) of the ESC. *Eur Heart J* 37, 2129-2381 (2016)
9 Dickstein, K. et al. ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure 2008. The Task Force for the Diagnosis and Treatment of Acute and Chronic Heart Failure 2008 of the European Society of Cardiology. Developed in collaboration with the Heart Failure Association of the ESC (HFA) and endorsed by the European Society of Intensive Care Medicine (ESICM). *Eur Heart J* 29, 2388-2442 (2008). This figure (15 million) is not included in the most recent ESC heart failure guidelines (2016) – see footnotes 7 and 8
identifies heart failure as a leading cause for hospital admissions, requiring on average longer stays in hospital than heart attacks.\textsuperscript{13}

The prevalence of heart failure in Europe is set to increase, due to an ageing population and occurrence of co-morbidity factors.

4. National health policy needs, focusing on health system improvements

Early diagnosis is key. For this, patients must learn to recognise symptoms of heart failure (breathlessness under physical and mental effort and swollen ankles/lower legs) and see their doctor as soon as possible. Also general practitioners, pharmacists and community nurses all need to be better trained to recognise non-specific symptoms. On suspicion of heart failure, they should initiate ECG and blood test. If the ECG and the blood test cannot rule out heart failure, the patient should be referred to a cardiologist to evaluate heart function, using echocardiography, to make the diagnosis and investigate the cause of heart failure. Equally, early initiation of appropriate treatment is crucial to relieve symptoms, prevent additional organ damage and improve prognosis.

People who are hospitalised due to coronary heart disease or acute heart failure need to be given appropriate after-care to ensure that chronic heart failure does not develop. This includes self-management, remote monitoring and timely interventions, as needed.

Heart failure patients may need support from a multi-disciplinary team. This team includes, in addition to the cardiologist, specialised heart failure nurses, dieticians, physiotherapists and coaching, so that patients can adopt and maintain a healthy lifestyle, i.e. adopt healthy diets, engage in physical exercise, and stop smoking, tailored to their specific condition and needs, and learn how to cope better with the significant changes in their lives due to the disease.

Depending on the patient, the general practitioner needs to ensure a close cooperation with the cardiologist, a specially trained heart failure nurse, as well as with other medical specialists, such as respiratory physicians, nephrologists, endocrinologists and psychiatrists.

Conclusions and recommendations

Successful prevention and treatment strategies have led to a significant decrease in deaths from cardiovascular disease over the past three decades. However, Europe’s ageing population and the occurrence of co-morbidities, such as hypertension, diabetes, obesity and kidney disease, is set to lead to an increase in prevalence of heart failure. Effective steps must be taken to curb the burden associated with heart failure at both a personal level, i.e. for patients and their carers, and at a health system level.

EHN recommends:

- to raise awareness of the symptoms of heart failure among the general public and those at risk
- to improve the diagnosis of heart failure through awareness-raising and better training of primary healthcare professionals leading to a swift referral to specialists
- that patients receive tailored support from a specialised multi-disciplinary team, as appropriate, to treat heart failure as well as co-morbidities

that research should focus on finding treatments, especially for heart failure with preserved ejection fraction, which can help the heart muscle work efficiently again, repairing damage and/or reducing overload

− to improve collection of data on heart failure across Europe and make them available in registries.

For more information visit the European Heart Network at http://www.ehnheart.org/

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