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POSITION PAPER

Self-care of heart failure patients: practical management recommendations from the Heart Failure Association of the European Society of Cardiology

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Self-care is essential in the long-term management of chronic heart failure. Heart failure guidelines stress the importance of patient education on treatment adherence, lifestyle changes, symptom monitoring and adequate response to possible deterioration. Self-care is related to medical and person-centred outcomes in patients with heart failure such as better quality of life as well as lower mortality and readmission rates. Although guidelines give general direction for self-care advice, health care professionals working with patients with heart failure need more specific recommendations. The aim of the management recommendations in this paper is to provide practical advice for health professionals delivering care to patients with heart failure. Recommendations for nutrition, physical activity, medication adherence, psychological status, sleep, leisure and travel, smoking, immunization and preventing infections, symptom monitoring, and symptom management are consistent with information from guidelines, expert consensus documents, recent evidence and expert opinion.

Keywords Self-care • Heart failure • Lifestyle • Patient education

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Introduction

Self-care is essential for patients with heart failure (HF), and improving self-care is a major focus of multidisciplinary HF management programmes worldwide. Self-care can be defined as a process of maintaining health through health promoting and preventive practices.[1] Patients with HF and more effective self-care behaviour have better quality of life and lower mortality and readmission rates than those with lower levels of self-care.[2,3]

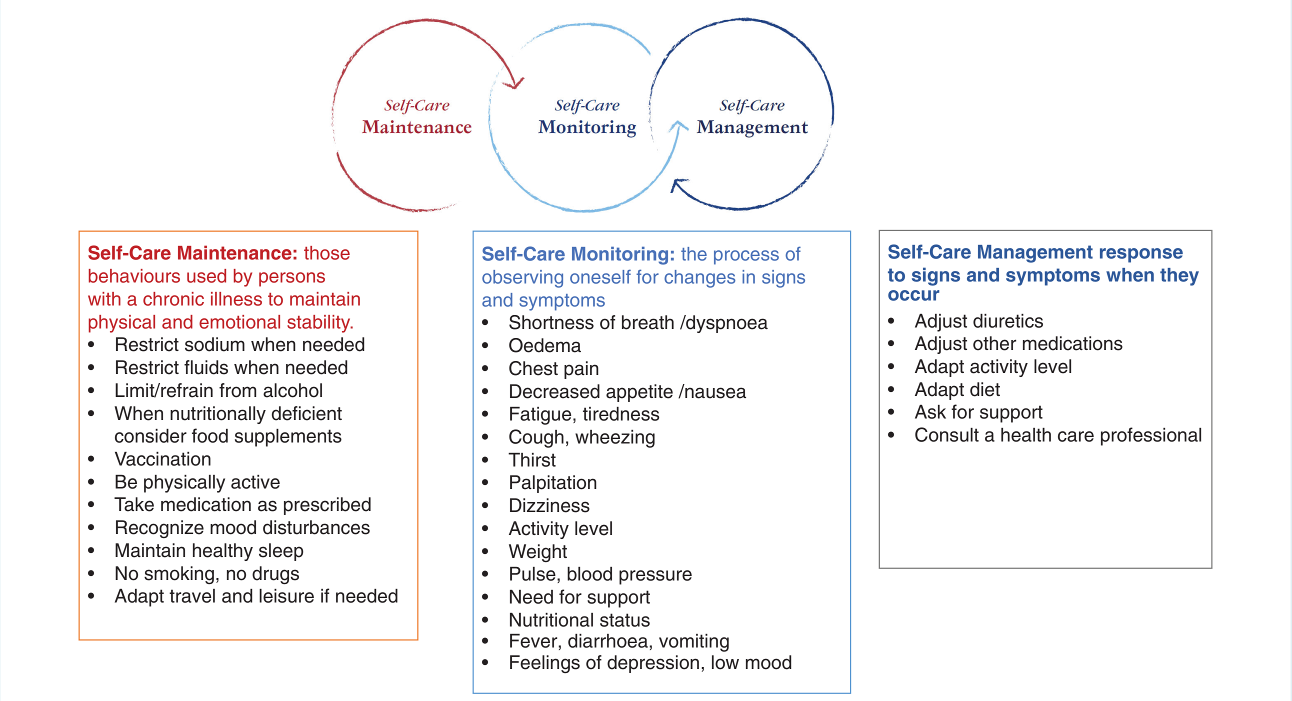
Multidisciplinary management programmes that focused on enhancing HF self-care significantly reduced HF and all-cause hospitalizations in patients with HF.[4] This is confirmed in an individual patient data meta-analysis from 20 studies, representing 5624 patients with HF, that found a beneficial effect of self-care interventions on time to HF-related hospitalization or all-cause death and HF-related hospitalization alone and HF-related quality of life.[4]

Although everyone (ill or healthy) is engaged in some level of daily self-care, the need for self-care and the value of specific guidance become more prominent once a person is diagnosed with a complex chronic syndrome such as HF. Misunderstandings, misconceptions, and lack of knowledge all contribute to insufficient self-care, and thus patient education is vital.[5]

Self-care is an overarching concept formed of the three key concepts of (i) self-care maintenance (e.g. taking or adjusting medication as prescribed, engaging in physical activity, and adhering to a healthy diet), (ii) self-care monitoring (e.g. regular weighing), and (iii) self-care management (e.g. changing diuretic dose in response to symptoms) (*Figure 1*). For patients with HF it may be necessary to regulate and adapt self-care during the disease trajectory, e.g. during periods of deterioration, when comorbidities develop, or when the patient requires more advanced therapies. In fact, at the time of writing this manuscript the world is fighting against the outbreak of COVID-19 (SARS-CoV-2 infection) by enforcing social isolation and distancing which has disproportionately affected patients with HF. In these circumstances, self-care maintenance, monitoring and management are even more important than usual to maintain HF stability and avoid deterioration of HF, which can lead to preventable contacts with the health care system, such as visits to the emergency room, visits to the general practitioner and recurrent hospital admissions.

Most guidelines state very general recommendations related to self-care behaviours. This is due to the lack of evidence on the effectiveness of separate self-care behaviours or on the effect of very specific recommendations, for example how often a person should weigh him/herself. At the same time there are several research studies and guidance documents that can help clinicians guide treatment and discuss decisions with patients.

The aim of this paper is to summarise guideline recommendations, other relevant data and documents as well as expert opinion related to HF self-care in order to provide practical management guidance to health care professionals caring for patients with HF, and to identify areas that require further research. This paper serves as an update to previous



Self-Care Maintenance: those behaviours used by persons with a chronic illness to maintain physical and emotional stability.

- Restrict sodium when needed
- Restrict fluids when needed
- Limit/refrain from alcohol
- When nutritionally deficient consider food supplements
- Vaccination
- Be physically active
- Take medication as prescribed
- Recognize mood disturbances
- Maintain healthy sleep
- No smoking, no drugs
- Adapt travel and leisure if needed

Self-Care Monitoring: the process of observing oneself for changes in signs and symptoms

- Shortness of breath /dyspnoea
- Oedema
- Chest pain
- Decreased appetite /nausea
- Fatigue, tiredness
- Cough, wheezing
- Thirst
- Palpitation
- Dizziness
- Activity level
- Weight
- Pulse, blood pressure
- Need for support
- Nutritional status
- Fever, diarrhoea, vomiting
- Feelings of depression, low mood

Self-Care Management response to signs and symptoms when they occur

- Adjust diuretics
- Adjust other medications
- Adapt activity level
- Adapt diet
- Ask for support
- Consult a health care professional

Figure 1 Self-care is an overarching concept based on three key concepts: (i) self-care maintenance (e.g. taking medication as prescribed, physical activity), (ii) self-care monitoring (e.g regular weighing), and (iii) self-care management (e.g. changing diuretic dose in response to symptoms).

Heart Failure Association (HFA) recommendations on self-care published in 2011.[6] We have updated and reshaped the 2011 document with research and recommendations published in the past 10 years, developed sections on monitoring, travel and leisure, smoking, and expanded the document to reflect patient preferences related to self-care. In general, advice related to self-care management is similar for patients with HF with reduced ejection fraction (HFrEF), patients with HF with mid-range ejection fraction (HFmrREF) and patients with HF with preserved ejection fraction (HFpEF); however, when relevant, we have added specific information for each ejection fraction category in this version of the paper. The manuscript is organized in such a way that for each aspect of self-care, statements from guidelines and additional evidence are summarized, advice to patients provided, and professional attitudes outlined. Each section concludes with recommendations for future research. The recommendations are categorized into self-care behaviours that help to maintain stability, monitor for changes, and respond appropriately to symptoms. (We added a separate table (*Table 1*) with advise to patients with heart failure regarding self-care, that can be found in the end of this paper).

Self-care behaviour to maintain stability

Maintain optimal nutritional status

Current guidelines and evidence

Body weight, obesity and cachexia

- Overweight is associated with deterioration in signs and symptoms of any type of HF, increasing left ventricular (LV) mass and LV strain. Cachexia is related to poor prognosis and associated with end-stage HF. In the morbidly obese patient, bariatric surgery can be offered to achieve at least 10% of weight loss and positive LV remodelling.[7–10] However, there are still controversies about the 'HF obesity paradox', where the patients with a higher body mass index (BMI), with confirmed diagnosis of HF, appear to have reduced mortality compared to those with a lower BMI.[11] Weight management in this large sub-group of patients remains unclear. There is limited data on the prognosis of HF patients with morbid obesity defined as BMI $\geq$40 kg/m^2; however, this group seems to have worse outcome (overall increased mortality similar to underweight HF patients); for this sub-group, a significant weight loss is important and related to decrease major health risks. Most likely a significant weight loss can be achieved by bariatric surgery.[12]
- Cachexia in HF is related to congestion, inflammation, malabsorption, anorexia, and neurohormonal over-activation, and as a consequence is associated with increased mortality.[9] In HF, it has been usually been defined as unintentional oedema-free weight loss of either >5% or as much as >7.5% in the preceding 6–12 months or BMI <20 kg/m^2, with evidence of sarcopenia, wasting and abnormal biochemistry.[10,13] Patients meeting cachexia criteria should be carefully reviewed by the HF team and receive optimized treatment, exercise advice, and nutritional support.

Fluid and salt intake

- *Fluid intake*: Guidelines suggest that patients should limit fluid intake to 1.5–2 L in severe HF to relieve symptoms, and increase intake (and/or reduce diuretics) in hot and humid weather or in case of fluid loss.[14,15] Very limited data with low level of evidence suggest that fluid restriction may reduce the risk for HF hospitalization,[16,17] whereas other reports suggest it is not helpful for improving outcomes and is worse for patients' quality of life.[16] Fluid restriction is believed to be especially important in patients with hyponatraemia, but in one observational study of hospitalized patients with HF and hyponatraemia, fluid restriction was not associated with a meaningful increase in serum sodium.[18]
- *Salt intake*: There is no robust evidence for benefits of limiting salt intake in HF. In New York Heart Association (NYHA) class III–IV HF, ingesting >3 g salt per day was associated with increased risk of hospitalization and death[19,20] whereas in NYHA class I–II HF, an intake of <2 g salt was associated with increased risk.[19] Others describe that sodium restriction is associated with increased risk of HF hospitalization.[21] A recent systematic review of nine trials involving 479 HFrEF patients was inconclusive.[22]

  Strict salt intake reduction is not recommended further than the recommendation for the general population by the World Health Organization for a healthy salt intake of <5 g a day (https://www.who.int/news-room/fact-sheets/detail/salt-reduction).

Alcohol

- The relation between alcohol consumption and cardiovascular (CV) disease is still controversial, even though the evidence base for overall harm is increasing.[23]
- There is an association of alcohol consumption, especially binge drinking, with supraventricular arrhythmias, especially paroxysmal atrial fibrillation which might precipitate, or worsen HF signs/symptoms. Abstinence might decrease arrhythmia burden.[24]
- Consuming more than the guideline-recommended alcohol volumes (two units per day in men and one unit per day in women) is associated with development of HF and therefore it is recommended that this level of alcohol intake is not to be exceeded. However, in alcohol-related HF, complete abstinence is advised, and if achieved is associated with significant clinical improvement.[14,25]

Nutrients, food and vitamin supplements

- Guidelines suggest checking iron (ferritin and transferrin saturation) levels to aid both in determination of the aetiology of HF (iron overload), but also to guide whether iron

supplementation is required. Intravenous iron has been found to improve quality of life, peak oxygen consumption and exercise capacity and to decrease HF readmissions.[14,26–28] Randomized controlled trials are ongoing investigating the impact of intravenous iron supplementation on mortality and hospitalizations.[29] Whether increasing dietary iron supplementation has any benefits in HF remains unclear as oral treatment was ineffective in increasing exercise capacity.[30]
- Hyperkalaemia occurs in up to 40% of patients with chronic HF. Hyperkalaemia is associated with poorer outcomes and with hospitalization and mortality in patients with HF and should be corrected. Hyperkalaemia can be iatrogenic, caused by concurrent drugs and nutritional/herbal supplements.[31]
- Deficiencies of specific nutrients (e.g. selenium, coenzyme Q10, zinc, iron, protein, thiamine) are associated with HF.[32] There is little evidence on the safe use of supplements. Although inadequate intake and low plasma levels of micronutrients have been associated with adverse clinical outcomes, evidence supporting benefit from therapeutic repletion is limited. Thiamine (especially in alcoholics), and coenzyme Q10 have the most clinical trial data for supplementation.[33,34] Other than in patients who are deficient in specific micronutrients, there is no clear role for routine micronutrient supplementation as a component of HF management.[10,32]

Clinical practice and patients' perspectives

Tailored advice for patients and their caregivers should be provided considering their actual food and fluid intake, symptoms and current medication use. Severely ill patients with HF with low quality of life and decreased life expectancy should not be burdened with extensive lifestyle changes which may be of limited benefit.

Professional attitudes and behaviour

- Do not judge others for their lifestyle choices or behaviour.
- Educate the patient on a healthy, varied diet. This can be done by a team member of the HF team and specialist consultation of a dietician might be needed.
- Because weight reduction may confer metabolic and functional benefits, it is reasonable to recommend weight loss for selected patients, especially if young, functionally limited by overweight, and morbidly obesity (e.g. BMI $>35\,\text{kg/m}^2$). However, weight loss may be especially challenging for patients and caregivers already managing chronic HF.[10]
- Ask during every outpatient encounter about food intake. It is reasonable for patients with HF to be screened for unintentional weight loss at least annually, because of the strong association between cachexia and adverse clinical outcomes. It is important to detect early weight loss and loss of appetite. Research primarily focused on cancer patients found that identification of so-called 'pre-cachexia' and the provision of tailored nutritional counselling, helped maintain nutritional status, improve treatment tolerance and clinical outcomes.[35] Such findings might be applicable to a HF population. Consider regular (twice yearly) blood tests to check for iron levels and other micronutrients if history suggests this may be required.[10]
- Offer counselling to those who present with malnutrition or alcohol dependency. Referral to nutritionist or dietician with CV expertise should be offered to patients with cachexia, morbid obesity, or unhealthy food intake. Consider referral for support (addiction expertise) if the patient wishes to stop drinking alcohol.
- Ask patients if they take any supplements (including vitamins) and the rationale for it. Supplements have not been studied in large randomized trials and the general recommendation is to gain these micronutrients from a varied diet to prevent depletion. Some supplements might be expensive, some contain high levels of sodium or potassium without the patient and health care provider knowing about it.

Recommendations for future research

- Weight management tailored for overweight patients with HF.
- Optimal fluid and salt management in patients with HF.
- The need for micronutrient supplementation in patients with HF.
- Optimal dietary advice for cachectic patients

Optimize exercise tolerance and resume sexual activity

Current guidelines and evidence

- Exercise training may improve functional capacity, quality of life and reduce hospitalization.[36]
- Guidelines recommend regular physical activity and/or exercise training, and specify that these are effective and safe in patients with HF.[14,25,37]
- Extreme athleticism is associated with several distinct adverse HF phenotypes, although direct causality is not established.[38]
- Sexual activity can be resumed for patients in NYHA class I or II and for patients who are in NYHA class III or IV if their condition is stable and optimally managed.[39]

Clinical practice and patients' perspectives

Physical activity advice should incorporate patients' views, preferences, needs and values.

Professional attitudes and behaviour

- Ask patients about physical activity and exercise tolerance as part of routine clinical encounters.
- Refer to an exercise-based cardiac rehabilitation programme.
- Support and be empathetic if a patient struggles or is scared of renewing exercise after diagnosis. Be aware that there are many different forms of exercise, and involve your patient in selecting which might be best.
- When selecting the exercise modality, the patient's preferences and abilities, age, concomitant diseases, leisure and working habits, logistical restraints, and the availability of exercise training facilities and equipment should be taken into account.[40] The

EXPERT tool can be used for a standardized and yet individualized training programme.[41]

- Training protocols need to be adapted to each patient with regard to intensity (aerobic and anaerobic), type (endurance, resistance, and strength), method (continuous and interval), application (systemic, regional, and respiratory muscle), control (supervised and non-supervised), and setting (hospital/centre- and home-based).[41]
- Recognise problems with sexual activity, the relationship between the patients' sexual problems and HF and offer pharmacological treatment for erectile dysfunction or specialist referral when necessary. Inform patients about energy consumption/exercise tolerance, and about the relationship between sexual problems and HF. Consider to involve the partner in these discussions.

Recommendations for future research

- Exercise programmes for specific HF populations such as patients with HFpEF, the very elderly, cachectic or frail patients.
- Role of effects of telerehabilitation in promoting exercise performance in patients with HF.

Optimize adherence to medication

Current guidelines and evidence

- The reasons for non-adherence are multifactorial and effective interventions include improving understanding of the benefits of HF medication and self-care, as well as access and trust in their provider and health system.[42]
- Patients who are non-adherent have significantly increased rates of hospitalization and decompensation.[43]
- Guidelines recommend the provision of patient education with a particular emphasis on adherence and self-care.[14]
- Depression,[42] frailty[44] and cognitive decline[45,46] are clinical factors that can affect adherence.
- Family members and informal caregivers have an important role in improving adherence to self-care.[47,48]

Clinical practice and patients' preferences

Many patients and family members demand and appreciate shared decision-making and health education. A respectful relationship is needed to optimally address adherence.[49] Polypharmacy should be carefully assessed and priority (survival, quality of life, symptoms, side effects) should be discussed with patients and caregivers. In patients with comorbidity, optimize drug use. For drugs with similar pharmacodynamic actions, give preference to evidence-based medication in target dose instead of combination therapy.

Professional attitudes and behaviour

- Avoid as much as possible polypharmacy.
- Provide written and verbal information on indications, benefits, dosing, effects and side effects and discuss practical issues such as optimal time schedule, what to do in case of missed dose, etc. This needs to be adapted to the needs of patients, their level of understanding and their preferences. Consider involving caregivers if the patient is agreeable and consents.
- Members of the HF team must be aware that several different factors affect adherence,[45] including polypharmacy associated with comorbidities, taking multiple doses per day, age, cognitive issues, patient's understanding, addiction and poor social support.[50]
- Check if the patient understands the role of each medication in their treatment, ask if they are taking their medications and ask if there are possible barriers for medication taking as a routine part of each clinical encounter. Discussing pharmacy records (if patients collect their prescription) might be an option to discuss possible barriers to adherence.
- Consider referral to other health care providers (e.g. psychologist, general practitioner, HF pharmacist) if necessary. Involve the multidisciplinary team in management plans in patients with complex comorbidities, including the general practitioner.

Recommendations for future research

- Approaches to improve monitoring and improving medication adherence including eHealth.

Optimize psychological status

Current guidelines and evidence

- A lot of patients with HF symptoms (NYHA class II–IV) suffer from anxiety and depression. The rate of patients with HF and depressive symptoms escalates to nearly 70% during hospitalization.[51] Depressive symptoms and anxiety might have consequences for other self-care behaviours (e.g. exercise, adherence), involvement in decision-making, and for family dynamics.[52] Depression is an independent risk factor for increased use of health care resources, with severe symptoms associated with increased mortality and hospitalizations.[51,53]
- Good psychological support is important to both patients and families.[14]
- Depression is associated with increased risk taking behaviour, poor adherence and social problems.[54]
- A systematic review and meta-analysis of 19 randomized controlled trials (3447 patients) demonstrated the benefit of exercise on wellbeing.[55]
- Antidepressants are safe in patients with HF and are not associated with increased mortality. However, there is inadequate evidence that the use of antidepressants effects significant improvement in depression or cardiac outcomes.[56,57]
- Interventions, such as Tai-Chi, yoga, meditation, relaxation, and stress management may improve quality of life and psychological status.[58–60] Cognitive behavioural therapy has been found to decrease depressive symptoms in patients with HF.[61,62]
- Family-based education can improve quality of life at 3- and 6-month follow-up.[47]

Clinical practice and patients' perspectives

Living with HF can be stressful and challenging, and patients often report mental distress such as anxiety and depression.[63]

Professional attitudes and behaviour

- Screen for anxiety and depression. Consider using self-reported questionnaires to assess mental health accurately and identify problems.
- Involve family (if agreed by the patient).[64]
- Regularly communicate information on disease, treatment options and self-care (e.g. exercise) and motivate patients to participate in non-pharmaceutical management, such as exercise, mindfulness, etc.
- Consider referral for psychiatric/psychological input as necessary.
- Ask the patient about work and financial concerns aggravating psychological responses; these could be remedied if the patient is eligible for benefits.

Recommendations for future research

- Optimal screening for and management of depression and anxiety in patients with HF.

Optimize sleep

Current guidelines and evidence

- Patients with HF often experience unsatisfactory and insufficient sleep (in quality and time) due to periods of pulmonary fluid overload resulting in orthopnoea, paroxysmal nocturnal dyspnoea and nocturia.[65]
- Psychological problems (anxiety, depressive mood) and obesity are commonly associated with insomnia in patients with HF.
- Studies suggest that almost 75% of patients with HF report sleep disturbance and poor sleep quality, with 44% reporting restless sleep and 41% having trouble falling asleep. Moreover, 39% experience early awakening and 32% have trouble returning to sleep after early or brief night awakenings.[66–68]
- Poor sleep quality may impact the ability of patients with HF to adequately perform self-care.[69,70]
- Sleep-disordered breathing affects over 50% of the patients with HFrEF.[65] As HF becomes more severe, the prevalence of Cheyne–Stokes respiration with central sleep apnoea (characterized by an oscillatory pattern of ventilation with hyperventilation-induced hypocapnia) increases markedly.[71] The other main type of sleep disorder prevalent in patients with HF is obstructive sleep apnoea (OSA). OSA is particularly common if the patient is overweight, diabetic, or has a large neck circumference or retro- or prognatism.[72] Furthermore, OSA is also regarded as one of the contributing comorbidities in HFpEF.
- Positive pressure mask therapy (CPAP) may be considered in HF and OSA. There is some evidence that the treatment of OSA in patients with HF with CPAP can improve symptoms, cardiac function, biomarkers of CV disease and quality of life, but the evidence for an improvement in mortality is weak.[65]
- Patients with HFrEF and predominantly central sleep apnoea should not receive adaptive servo-ventilation because it can lead to a higher death rate.[71]

Clinical practice and patients' perspectives

Problems with sleeping should be part of clinical assessment, and underlying causes, such as fluid overload, OSA or psychological problems such as anxiety and depression, should be diagnosed and addressed with an intervention.

Professional attitudes and behaviour

- Be aware that insomnia may cause significant mental and physical health problems. Routinely ask for the nature and quality of sleep. Check if patients are feeling rested after sleep.
- When patients describe sleep disorder, check if patients are euvolaemic.
- Perform appropriate depression and anxiety scores and consider referral for psychiatric/psychological input as necessary.
- Consider asking the partner of the patients about sleep problems. They might report that the patient snores, has sleep apnoea or exhibits daytime sleepiness, although the latter may be infrequent due to sympathetic stimulation.[73]
- Where sleep-disordered breathing is suspected, perform a formal sleep study to confirm the diagnosis and type of apnoea.
- In the presence of OSA, provide advice on weight reduction/control (if relevant) and advocate for the regular use of CPAP for at least 6 h per night. Consider and carefully discuss the benefits and deleterious effect of sleep medication. Benzodiazepines are generally discouraged due to the possibility of tolerance and addiction. In older adults, benzodiazepines can impair cognition, mobility, and driving skills and increase the risk of falls. Antihistamines are safe but can cause daytime sleepiness. There is no evidence regarding the use of melatonin in HF. Zopiclone is used more frequently and is generally considered safer than benzodiazepines.[74,75]

Recommendations for future research

- Effects and long-term clinical consequences of use of sleep medications in patients with HF.
- Determinants of sleep quality in patients with HF and associations with comorbidities.
- Interaction of sleep quality in patients with HF and ability to self-care.

Adapt travel and leisure

Current guidelines and evidence

- *Air travel*: There is an increased incidence of CV events during travel for persons who have existing CV disease,[76] with cardiac causes representing 8% of medical emergencies during air travel.[77] Among cruise ship passengers, HF decompensation represents approximately 4% of CV emergencies.[78] Moreover, patients with HF are at higher risk of developing deep vein thrombosis and pulmonary emboli during long haul flights.[79,80]
- Passengers with stable HF, without recent changes in symptoms or medications, are usually able to tolerate air travel and the associated mild hypoxia.[79,81,82]
- For patients with stable HF including NYHA class III and IV, hypoxia up to 1 h at rest produces no significant deleterious effects.[81,83] Take care of pulmonary hypertension, even if the NYHA class is low. Periods of up to 7 h (long haul) are tolerated by those with mild to moderate stable HF (NYHA class II).[84] Severe decompensated HF poses serious challenges to air travel.[85]
- *Change in climate*: Colder climates can increase peripheral vascular resistance and thereby increase myocardial oxygen demand, making it easier to reach the ischaemic threshold resulting in and worsening anginal symptoms for patients with ischaemic cardiomyopathy.[6]
- *Altitude*: Depending on NYHA class, patients may safely reach high altitude of up to 3500 m (NYHA class I–II) or 3000 m (NYHA class III). Being at high altitude, no greater intensity than moderate physical activity is recommended. It is prudent not to exceed an ascent rate of that recommended for healthy travellers (300–500 m/day when above 2500 m).[86]
- *Stay abroad*: Travel also may be associated with a change in lifestyle related to food and alcohol intake and diuretic dose may need adjustment to avoid decompensation.
- Gastro-intestinal upset is quite common when a patient is exposed to alien bacterial flora, which, coupled with sweating in hot climate, may cause dehydration. A practical individualized advice might include to reduce or stop diuretics, drink an additional 500–1000 mL of non-alcoholic drinks and if the body weight is back to normal the patient can restart the usual medicines. Some patients might even be advised in case of weight loss and/or symptomatic hypotension, to temporary reduce the doses of the diuretics and/or angiotensin-converting enzyme inhibitors/angiotensin receptor blockers/angiotensin receptor–neprilysin inhibitors.
- *Driving*: The Driving Licence Committee of the European Union amended its Directive 2016/1106 of 7 July 2016[87] and states that driving licences may be issued to or renewed for applicants or drivers in NYHA class I, II, III (if stable) for motor cycles, passenger cars and other small vehicles with or without a trailer (group 1). Driving licences shall not be issued to or renewed for applicants or drivers in NYHA class IV.
  Related to professional driving or heavy vehicles [vehicles over 3.5 t or vehicles designed for the carriage of more than nine passengers (including the driver)] (group 2), drivers in NYHA class I and II, driving licences may be issued or renewed provided that the LV ejection fraction is at least 35%. Driving licences shall not be issued for professional driving or heavy vehicles to NYHA class III and IV. Other conditions such as syncope, arrhythmia and treatment should be considered.

Clinical practice and patients' perspectives

Many patients with HF are keen to travel, both for business and leisure. Education, planning and access to timely review when necessary are important to help avoid anxiety and ensure the possibility of safe travel.

Professional attitudes and behaviour

- Inform and discuss medical and practical issues related to travel.
- A clinicians advice regarding a patient's fitness to drive should include consideration of the patient's level of knowledge and insight into their medical condition, ability to manage the condition, adherence to prescribed treatment and ability to modify driving activities to accommodate their medical condition.[88] For patients in NYHA class I, II or III no restriction (if not complicated by syncope, arrhythmia or other diseases and treatment) for driving is needed for private transportation. For professional driving, additional rules apply (patients must be in NYHA class I or II and LV ejection fraction ≥35%).[87]

Recommendations for future research

- Do HFrEF and HFpEF patients have similar physical adaptations to travel?
- What are the effects of long-distance car/coach/air travel in patients with HF?

Immunization and preventing infections

Current guidelines and evidence

- Influenza infection is an important trigger for CV events.[89]
- Patients with HF are vulnerable to viral infections (like the recent COVID-19).
- Influenza vaccination is associated with a significant decrease in all-cause mortality risk in patients with HF, as recently shown in a meta-analysis of 179 158 patients which included patients with HF.[90]
- Guidelines advise yearly immunization against influenza and a one-time only vaccination against pneumococcal disease.[14]

Clinical practice and patients' perspectives

Importance of vaccination needs to be discussed in an open manner and worries of patients and families should be discussed.

Professional attitudes and behaviour

- Discuss benefits and possible barriers.

- Advise on local immunization practice, routines, and reimbursement.

Recommendations for future research

- Optimal intervention to protect patients with HF from infection and its complications.

Refrain from smoking and drugs

Current guidelines and evidence

- Professional HF guidelines recommend that patients should be counselled to avoid smoking as well as illicit drug use.[14,91]
- Use of e-cigarettes is not advised as there is significantly higher risk of CV diseases among dual users of e-cigarettes + combustible cigarettes compared with smoking alone.[92]
- Waterpipe use exposes smokers to significantly higher levels of heavier and more toxic polycyclic aromatic hydrocarbons than cigarette smoking, as well as cardiorespiratory toxicants such as volatile organic compounds and heavy metals such as cadmium and lead that can injure the blood vessels and the brain.[93]
- Cocaine, amphetamine, 'ecstasy', cannabis, lysergic acid diethylamide (LSD), psilocybin ('magic mushrooms'), volatile substance, narcotics, all can induce major acute changes in CV function, and may also cause irreversible damage to the heart.[25,94]

Clinical practice and patients' perspectives

Although it seems obvious to professionals that patients with HF should not smoke or use illicit drugs and they may assume that patients quit after their cardiac diagnosis, a lot of patients with HF are active smokers (13–54% patients).[95] Engaged, patient-centred smoking and drug cessation counselling requires health professionals to listen to patients early in the process. Patients desire honest, consistent, and pro-active discussions and actions.[96]

Professional attitudes and behaviour

- Ask patients about tobacco use, e-cigarette use, waterpipe (Hookah/Shisha/Hubble bubble) and use of recreational drugs as part of routine clinical encounters.
- Associated psychosocial issues often occur alongside drug abuse and should also be considered.
- Consider referral for support if the patient wishes to stop smoking or taking drugs.
- Become familiar with the principles and practice of cessation, including the use and prescription of validated pharmacotherapies in case of smoking cessation (nicotine replacement therapy, such as bupropion, varenicline) with caution for CV side effects and CV drug interactions.
- Provide clear, concise, unambiguous, and non-judgemental advice regarding the importance of cessation and offer specific assistance (e.g. cognitive behavioural therapy and psychological support) in initiating a cessation attempt.[1,97]
- Be aware that illicit drug use and smoking preclude heart transplantation.
- Be aware that illicit drug use is often associated with significant social issues (e.g. homelessness) with associated concomitant lack of adherence and engagement with health care teams.

Recommendations for future research

- Risks and prevalence of recreational drugs in patients with HF.

Self-care behaviour to monitor for changes

Deterioration of HF or development of new symptoms can be devastating for patients, significantly affects quality of life and worsens outcomes. Numerous studies have investigated self-management,[98] but none specifically self-monitoring. No specific programme characteristic is clearly associated with better outcomes.[99] Still, most self-management programmes include self-monitoring.[100] Monitoring should include signs and symptoms of HF, of comorbidities and of side effects of medication.[101]

Symptom monitoring (self-monitoring and telemonitoring)

Current guidelines and evidence

- Guidelines recommend monitoring of signs and symptoms of HF as an integral part of self-care.[14] Monitoring may be undertaken by the patients themselves, in person by clinicians, by remote monitoring (with or without implanted devices) including structured telephone support.[14]
- Several meta-analyses have suggested clinical benefits from remote monitoring.[102] The TIM-HF2 study demonstrated prognostic improvement in the context of a 24/7 support system.[103]
- Monitoring using implantable devices may improve outcomes. This includes remote monitoring of pulmonary artery pressure using the CardioMEMS device[104] or multiparameter monitoring based on implantable cardioverter-defibrillators.[105]

Clinical practice and patients' perspectives

Early detection of a deterioration in HF symptoms is important in order to prevent hospital admission and increased mortality. Patients should receive education in symptom monitoring at diagnosis, with a management plan discussed and agreed on how this could be safely and effectively delivered in the future. Monitoring over the course of the patients' lifetime can be done in a variety of ways, with patient preference and resource availability directing choice. The current COVID-19 pandemic has ensured a renewed focus on remote monitoring.

An easy guidance to help patients with HF to monitor themselves is depicted in *Figure* 2. The frequency of monitoring should depend on clinical status and stability. The monitoring interval should be short (e.g. days) if the clinical condition or medication has been changed, but is needed for at least every 6 months for patients with stable HF.[106] However, evidence is lacking to support these recommendations.

Professional attitude and behaviour

- Arrange for reading support (e.g. reading the weighing scale or monitoring equipment) and interpreting the results if necessary, e.g. from a family member, home care or the HF team.
- Recognize changes and know how and when to contact a health care professional.
- Call the HF team if you are acutely unwell with diarrhoea and/or vomiting that persists more than one day.
- Consider support by informal caregivers if the patients prefer.
- Consider using telemonitoring.

- Be aware that patients have different degrees of both health literacy and technology and computer skills and that consequently there is no single way a group of patients should be monitored. Help patients to assess symptoms and to react appropriately. Consider the need to assess:
    - Frequency (how often)
    - Intensity (e.g. on scale 1–10)
    - Rate (on how many occasions during a time interval)
    - Duration (how long)
    - Pattern (mornings, after activities, etc.)
    - Specificity of the symptom (e.g. pain in the whole body, arms, etc.).

Green – Monitor your symptoms - Safety Zone

- No changes in your breathing
- No changes in leg or abdomen swelling
- No additional new symptoms (such as dizziness, quickening heart rate)
- If applicable, your telemonitoring application does not provide any alerts
- Weight stable/no change in your weight
- You are as active as usual

Continue to weigh daily, take medications as prescribed, make sure you keep your appointments

Amber - Contact your HF nurse or GP for advice if symptoms persist – Warning Zone

SEEK HELP TO AVOID DETERIORATION AND POSSIBLE ADMISSION TO HOSPITAL

- Breathing is more difficult than usual and/or worsens on lying down/awakens you during night
- Legs or abdomen increasingly swollen
- New symptoms are present that may be related to your heart condition
- If applicable, your telemonitoring application asks you to contact your HF nurse/doctor
- Weight has increased 4 lbs/2 kg or more over 2-3 days
- Your medications have been changed and your HF team is not aware

Continue to weigh daily, take prescribed medications, follow advice given from specialist team as regards altering medications and ensure you have any requested bloods tests

Red - Contact your HF nurse/GP immediately or go to emergency department – Alert Zone

SEEK HELP AS SOON AS POSSIBLE

- **Unrelieved breathlessness whilst resting**
- **New onset chest pain – not relieved by medication**
- **Persistent rapid heart/palpitation, either with or without symptoms or at a rate of >140 bpm**
- **If applicable, your telemonitoring system tells you to seek help**
- **You have had a blackout or feel like you may have one**

Figure 2 Guidance for self-care monitoring and self-care management of patients with heart failure (HF). GP, general practitioner.

- Telemonitoring may be considered to support patients in self-monitoring, though best practice is not yet defined. Several digital health applications are available to monitor symptoms and patients may want to use them to keep track of their symptoms and share the data with health care professionals. It should be an integral part of care, but the best approach is not yet defined and may vary among patients (*Table 3*).

Recommendations for future research

- Transition from a face to face review with the HF team to joint virtual/face to face service.

Monitor side effects, adverse effects and complications

Current guidelines and evidence

- Adverse effects and side effects of HF medications are documented as high as 10% in clinical trials and up to 17–22% in observational studies.[107,108] Side effects commonly lead to non-adherence to HF treatment, but up to one-third of patients experiencing such problems do not inform their health care providers.[108] It can be difficult for both patients and health care professionals to separate disease symptoms from drug-related side effects.[109]
- Professional HF guidelines strongly recommend education of patients of the common side effects of HF medications.[14,15] Provision of information on adverse reactions is suggested, as well as counselling about when to notify health care professionals about drug-related symptoms.
- Patients who report on side effects are described to have lower general health perceptions, stronger general beliefs about medication overuse, having neurotic personality, are more often female and in higher NYHA functional class.[108,110–112]
- The concern about medication-attributed hypotension is frequently exaggerated among both patients and clinicians. Importantly, asymtomatic hypotension is no reason to reduce medication or to avoid up-titration in patients with HFrEF. On the other hand, evidence suggests intensive blood pressure control in older persons compared with standard treatment does not exacerbate orthostatic hypotension and does not increase the risk of injurious falls.[113]
- Initial data on the use of eHealth tools for patient self-monitoring show significant increases of positive changes in medication use; however, currently there is little or no evidence to support their effectiveness for identification of side effects or improving patient satisfaction.[114]
- Renal function changes are often considered an adverse reaction to renin–angiotensin–aldosterone system inhibitors in HFrEF; however, up to date evidence shows that mortality benefits are maintained despite worsening renal function.[115]

Clinical practice and patients' perspectives

Almost half of the patients with HF consider medication side effects to be a serious challenge caused by this disease and believe that health care professionals can prevent, alleviate, or control these adverse reactions. Clear advice about rationale for use, possibility of modification and shared decision-making can help to cope with adverse effects, which highlights the importance of an open and effective relationship between the patient and the health care professional.

Professional attitudes and behaviour

- Adjust the medication regimen in case of side effects, explain the reasons and share with the patient an informed decision about how to cope with the side effect.
- Counsel all patients and their preferred caregivers to recognize and act upon common side effects of HF medications.
- Advise patients to seek medical help immediately in case of swelling lips or throat.
- Counsel patients on how to reduce risk of falls.
- Start HF medications at a low dose and increase in small steps to improve tolerance.
- Rule out pulmonary congestion and heartburn as a cause of cough prior to discontinuing angiotensin-converting enzyme inhibitors.
- Recommend patients not to skip the diuretic therapy when they are away from home, but encourage them to choose the optimal timing of taking the diuretics according to their peak urination and planned trip, for example, upon returning home.
- Help patients to document a history of side effects.
- Be aware that associated colleagues might need an explanation in terms of worrisome blood pressure or renal function.
- Report the adverse event in the patient's records.

Recommendations for future research

- Strategies to prevent and/or reduce the frequency of drug-attributed side effects.

Self-care Management behaviour

Self-care behaviour to respond appropriately to symptoms

Appropriate responses to symptoms include patients adjusting their diuretic dose, contacting a health care provider, and decreasing activity level as well as fluid and salt intake.

Current guidelines and evidence

- HF guidelines recommend diuretics to improve symptoms and exercise capacity in patients with signs and/or symptoms of congestion, and they should likewise be considered to reduce the risk of hospitalization in these same patients.[14]

- A flexible and individualized diuretic dosing regimen may improve quality of life and help reduce emergency department visits and HF-related hospitalizations in patients with HFrEF.[116]
- Despite the guideline recommendation to use the lowest possible dose of diuretics and discontinue loop diuretics if possible, little information is available on discontinuing loop diuretics in contemporary treated patients with HF.[117,118]
- Adjustment of diuretic therapy (often an increase) may improve outcomes.[104]

Clinical practice and patients' perspectives

Reactions to symptoms need to be adapted to the individual patient. Due to changes in the patients' condition (either HF related to other reasons) the medication regimen might need to be changed (see part on side effects and medication), physical activity level and exercise training decreased, or a (temporary) change in their sodium or fluid intake needed.

Furthermore, diuretic therapy is used to treat signs and/or symptoms of congestion.

The goal of diuretic therapy is to achieve and maintain euvolaemia with the lowest achievable dose. However, clinical assessment of euvolaemia may be difficult and many patients remain congested despite increase in HF therapy.[119] The dose of the diuretic must be adjusted according to individual needs over time. A patient-directed flexible diuretic dosing schedule based on personalized variation in fluid-related signs and symptoms is safe in patients with chronic HF. Some patients and families might not feel comfortable making decisions to change medications or lifestyle and need support from the health care providers.

Professional attitudes and behaviour

- Provide individualized information to support self-care management to patients and caregivers. Patients may adjust diuretic therapy and/or alert their health care team in case of increasing signs and symptoms (e.g. dyspnoea, oedema, hypotension), or a sudden unexpected weight gain of >2 kg in 3 days as a rule of thumb; however, this may need to be tailored to the individual patient.
- In selected euvolaemic/hypovolaemic patients, the use of a diuretic drug might be (temporarily) discontinued.
- In patients with severe generalized congestion, especially in those with gut oedema, the effect of oral furosemide may be altered due to inadequate gastro-intestinal absorption. A change in diuretics or a switch to intravenous furosemide is recommended in order to increase diuresis, reduce generalized congestion and gut oedema and re-establish gastro-intestinal absorption for oral diuretics.
- Renin–angiotensin–aldosterone system inhibitors and diuretic therapy continued during acute hypovolaemic illness significantly increase the risk of acute kidney injury and/or hyperkalaemia. One or more of these agents may need to be temporarily stopped or its dose reduced during illness. Particularly the diuretics and mineralocorticoid receptor antagonists migth need to be reduced/temporarily stopped (early).

Recommendations for future research

- Indication and consequence of flexible diuretic dosing strategies.
- Decision-making about how to manage particular symptoms.

Concluding remarks

This paper aimed to summarize practical recommendations that can help to improve self-care behaviour in patients with HF. Self-care is very important to improve patient outcomes, including quality of life and lower mortality and readmission rates. However, despite the obvious relationship between good self-care and positive health outcomes, many patients find it difficult to adhere to self-care advice, probably due to lack of motivation, ability or support. Health care professionals have an important role to inform patients, teach skills, adapt information, support individual needs and abilities and to engage with patients to make shared decisions.

Self-care is not meant to be synonymous with 'doing it all by yourself'. Informal caregivers, such as family or friends, can be involved if the patient prefers in all aspects of self-care (maintenance, monitoring and management) and this should be recognized by health care professionals. Materials and tools that can be used to support self-care are numerous and although the presentation of those is outside the scope of this document, we would like to specially mention the website 'heartfailurematters.org', that has a dedicated section on self-care behaviour.[120]

Measurement of HF-related self-care behaviour is advised when testing behavioural change interventions, for example with the 9-item European Heart Failure Self-care Behaviour scale[121,122] or the 29-item revised Self-Care of Heart Failure Index.[123] These questionnaires are valid and reliable to measure HF self-care behaviour and are available in several languages and used in research studies and can be considered to use in clinical practices to guide patient education. In addition, there is room to improve measurement of symptoms and factors related to self-care with valid and reliable instruments.

In this paper we have reviewed the specific self-care behaviours needed for most patients with HF. However, most patients have several comorbidities that can affect the self-care behaviour required (e.g. which diet to adapt, which symptoms to monitor) and also affect their ability to change behaviour (e.g. depression might hinder physical activity and decrease adherence to medications) or to implement advice (e.g. in case of cognitive problems). In addition, factors for example cultural aspects, economic restraints, and access to care need to be considered when giving advice on self-care behaviours.[124]

Table 1 **Advise to patients with heart failure regarding self-care**

Self-care maintenance

Maintain optimal nutritional status

- If you have a body mass index $>35\,\mathrm{kg/m^2}$ consider weight reduction since this might improve your functional capacity and quality of life. Please consult a dietician if possible. The general recommendation is to promote healthy lifestyle and weight loss, preferring plant-based food (fruit, vegetable, seeds, nut, legumes, whole grain cereals) over animal-based, processed foods and added sugar. Among animal-based aliments, fish and fermented dairy should be preferred over meat, minimizing the intake of red meat.
- Unintentional weight loss may be a sign of deteriorating heart failure and impending cachexia and should be brought to your health care providers' attention.
- Avoid excess of salt intake, that is keep <5 g a day (just under a teaspoon). This can be done by not adding salt during the preparation of food; not having a saltshaker on the table; limiting the consumption of salty snacks and choosing products with lower sodium content.
- Avoid large amounts of fluid intake. Adapt fluid intake in times of high heat and humidity, nausea/vomiting.
- Limit alcohol intake to two units of alcohol per day if you are a man and one unit if you are a woman, or no intake if alcohol has caused or contributed to your heart failure.
- In case of nutrient or vitamin deficiencies, supplementation may be considered, but there is no clear role for routine micronutrient supplementation. Some 'natural' or herbal supplements may interact with medication or might be high in potassium. Seek advice from the heart failure team before considering their use.
- If you have recurrent hyperkalaemia (high potassium level), the amount of potassium-containing foods and supplements should be limited.

Optimize exercise tolerance

- Undertake daily and regular exercise and be physically active, such as walking, cycling, swimming, jogging, rowing or light weight exercise
- Ask your heart failure team for advice if you have questions regarding whether it is safe to exercise, and which exercises suit you best.
- Adapt physical activity to your symptoms and personal preferences.
- If possible, undertake regular exercise at a level sufficient to provoke mild or moderate breathlessness.
- For some: extreme athleticism should be avoided.

Sexual activity

- If your heart failure is stable, be reassured about engaging in sex, provided sexual activity does not provoke undue symptoms. If erectile dysfunction is a problem, ask for advice on possible treatment.

Medication taking

- Try to engage in the management of your medication, understand the rationale, benefits and potential adverse effects of medical therapy.
- If preferred, encourage a family member to join you when your medicines are discussed.
- Ask for help if needed from family and friends.
- Discuss with your health care provider(s) anything that is hindering you from taking your medicines.
- Consider use of tools/aids to help remind you to take your tablets, such as a dosette box, electronic reminders, phone cues, etc.
- When starting heart failure medication, you may temporarily feel fatigue or tiredness; this is common, and is usually resolved after a few weeks.
- Because several heart failure medicines can cause dizziness, spacing individual drugs out at different times throughout the day may help. In case of dizziness, it can help to elevate your legs or stand up slowly.
- To limit disturbance of daily life caused by diuretics consider taking diuretics in the morning or up to lunchtime.
- Let your health care provider know if you think you are having a side effect.

Optimize psychological status

- Try to recognize concerns and worries and try to ask for help.
- Consider attending support groups to where patients can exchange views and understandings.
- Consider talking to family and friends, or a health care provider about your concerns/worries.
- Try to be physically active, even when you feel down.

Optimize sleep

- Be aware that good sleep promotes health.
- Insomnia is common and if it occurs, begin with 'sleep hygiene' activities such as avoiding caffeine late in the day.
- Consider doing relaxing activities before sleep. Yoga and mindfulness in the evening can improve sleep, as can a short walk outside. Consider avoiding TV, mobile phone, or computer use in the last hour before sleep.
- Consult your health care provider if you need to use more pillows at night due to shortness of breath (orthopnoea), suffer from recurrent awakening during the night (paroxysmal nocturnal dyspnoea), or experience sleep apnoea.

Table 1 (Continued)

Self-care maintenance

Adapt travel and leisure

- Plan travel and leisure activities according to symptom burden and physical capacity.
- Consider train travel instead of air travel if possible, depending on the length of travel.
- Wear compression stockings during travel when movement is curtailed.
- Discuss travel plans with the heart failure team.
- Ensure that appropriate travel insurance has been obtained.
- Take your medicines in the cabin luggage on the plane and the same amount also in the checked-in luggage, and ensure you have sufficient quantities for the whole duration of the trip, carry a list of medication in English (dosages and the generic names) and of the device name if relevant and obtain the list of medical centres at your destination treating patients with that same device.
- Monitor symptoms and adapt fluid intake and diuretic therapy according to humidity and altered salt intake in the diet.
- Be aware of adverse reactions to sun exposure with certain medication (such as amiodarone).
- Be aware that some airlines stipulate advance information in the case of ‘at-risk’ passengers.
- Consider local/national/international regulations related to driving with heart failure or/an implantable cardioverter-defibrillator.
- Patients in NYHA class IV are advised against driving.

Immunization and preventing infections

- Get immunization for influenza and pneumococcal disease.

Smoking and drug use

- Stop smoking (cigarettes, e-cigarettes, waterpipe).
- Do not use recreational drugs.
- Seek advice and support to stop smoking or using drugs. Encourage family members and friends to support you.

Self-care monitoring (*Table 2*)

- Monitor signs and symptoms of heart failure
- Monitor other symptoms such as deterioration of comorbidities and dehydration
- Monitor side effects
- Monitor response to self-care management behaviours

Self-care management

- Low blood pressure readings without symptoms are no reason for concern.
- Adjust diuretic dose according to the advice received by the heart failure management team, mainly relative to symptoms and weight variation.
- Do not hesitate to contact a health care professional if in need of support and advice.
- Ask your health care provider which strategy to apply for specific symptoms.
- Do not hesitate to contact a health care professional, e.g. your general practitioner or the heart failure team, when in doubt.

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Table 2 Changes for patients with heart failure to self-monitor

What to monitor	Why monitor? Possibly related to
Symptoms and signs	
Shortness of breath /dyspnoea	Fluid overload, increased afterload (relatively high blood pressure), comorbidities (chronic obstructive pulmonary disease), cardiac ischaemia
During activity (walking flat, walking stairs)	
Lying flat/at night	
During activity	
Oedema (legs, hands, ankles, thighs, scrotum, waist, abdomen)	Fluid overload
Chest pain	Cardiac ischaemia, fluid overload, increased afterload (relatively high blood pressure), comorbidities, anxiety
Decreased appetite/nausea	Fluid overload, anxiety, renal impairment
Fatigue, tiredness	Fluid overload, progression of heart failure, side effect of medication, sleep problems, anaemia
Cough, wheezing	Fluid overload, side effect of medication, comorbidities (chronic obstructive pulmonary disease) increased afterload (relative increase in blood pressure)
Thirst	Dehydration, progression of heart failure, side effect of medication (diuretics)
Palpitations	Arrhythmia
Dizziness	Low blood pressure (side effect), severity of heart failure, arrhythmia, dehydration
Reduced activity level	Clinical deterioration, anaemia
Weight: regularly/daily in same conditions (e.g. after morning toilet, in light clothes), using same weighing scale	Sudden weight gain: fluid overload Weight loss: malnutrition, sudden dehydration
Pulse	Fluid overload, arrhythmia, severity of heart failure
Blood pressure	Side effect of medication, hypertension/orthostatic hypotension
Other issues to monitor/assess	**Why monitor?**
Need for support	Practical and emotional support might be needed
Nutritional status/food intake	To prevent malnutrition
Fever, diarrhoea, vomiting	Possible need for adapting medications, fluid intake, diagnose acute comorbidities
Depressive feelings, low mood, anxiety	Possible deterioration, need for support
Response to self-care management behaviours	Possible need to confirm or change reactions to symptoms in future

Table 3 Self-monitoring of signs and symptoms with telemonitoring devices (invasive and non-invasive)

Weight	Sudden weight gain: fluid overload Sudden weight loss: hypovolaemia
Pulse	Fluid overload, arrhythmia, severity of heart failure
Lung impedance	Fluid overload, hypovolaemia
Blood pressure	Side effect of medication, hypertension/orthostatic hypotension
Pulmonary artery pressure	Fluid overload, increased afterload
Activity monitor	Severity progression of heart failure, comorbidities
Oxygen saturation	Fluid overload, comorbidities (chronic obstructive pulmonary disease)

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