

guideline summary palliative care in heart failure

Date of approval of guideline:
februari 2018 | version 3.0

Accountability: Guideline working group
on palliative care in heart failure

It is vital that as a care provider you are familiar with this guideline. For the most recent version of the guideline go to www.pallialine.nl/hartfalen or see the summary in the PalliArts App.

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Life expectancy in heart failure NYHA class III and IV

In daily practice, there are no suitable models to estimate the life expectancy of patients with heart failure NYHA class III - IV.

Without a prognostic model, recognise the patient with a poor life expectancy on the basis of the following characteristics:

- frequent re-admissions for heart failure with exacerbations
- persistent symptoms despite optimal treatment
- significant weight loss
- dependence in activities of daily life (ADL)
- severe comorbidity
- a negative answer to the surprise question: 'Would I be surprised if this patient died within the next 12 months?'
- no possibility of heart transplant or LVAD or the patient refuses this

Palliative care in heart failure NYHA class III and IV

What is understood by the term palliative care and how should it be structured?

- Focus on all dimensions of being ill: physical, psychological, social and spiritual. Use an interdisciplinary approach. Provide fundamental palliative care in all these areas. Identify symptoms and problems for which consultation and/or referral is necessary in a timely manner.
- Together with the patient, draw up an individual care plan based on the individual values, wishes and needs of the patient in all of the areas mentioned above. Anticipate situations that could arise in the future. Focus on the desirability (or otherwise) of admission to hospital, and discontinuing, or not implementing, measures aimed at preventing sudden heart death.

- Ensure that the individual care plan is accessible to the patient and all health care professionals involved. If necessary, revise the care plan during the disease process.
- Actively involve the informal carer and family and friends in the care. Focus on the resilience, the burden, the values, wishes and needs of the informal carer and family and friends (both during the disease process and after death).
- If necessary, consult the guidelines on palliative care on www.pallialine.nl.
- If symptoms are difficult to treat and/or complex problems arise, ask the experts for advice - a specialist palliative team for example - and/or for a referral to specialist health care professionals.

What is the effect of palliative care on heart failure?

Conclusions from literature studies:

- 83% of the studies show improvement in quality of life
- reduction of dyspnoea and sleep disorders, depression and anxiety
- 67% of the studies show improvement in level of satisfaction
- 71% of studies show better documentation of wishes and preferences of patients
- 70% of the studies show a reduction in medical consumption (attendances at Emergency Department, number and duration of hospital admissions, admissions to an intensive care unit, and visits from the GP)
- 42% of studies show a reduction in numbers of re-admissions following palliative consultations at home after discharge from hospital
- 50% of studies show an increase in dying at home, and 20% show an increase in hospice admissions

How is care tailored to the stage of palliative care?

- On worsening of disease and/or vulnerability, the occurrence of complications or functional deterioration, as the health care professional involved you should ask yourself the surprise question: 'Would I be surprised if this patient died within the next 12 months?'

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- If your answer to the surprise question is 'no', then have a discussion with the patient, after first establishing the extent to which the patient is willing to have such a discussion. Discuss scenarios that could potentially occur in the course of the illness, and, if necessary (and acceptable to the patient), broach the subjects of the wishes and expectations of the patient in respect of the future and the end of life.
- Start palliative care early. Criteria for this are:
 - a negative answer to the surprise question
 - unplanned admissions to hospital
 - a low or deteriorating functional status, with limited possibilities of recovery (WHO performance status 3: spending 50% or more of the day in bed or on a chair)
 - dependence on others for care needs, due to physical and/or mental problems
 - the informal caregiver needs more help and support
 - significant weight loss over preceding months, persistently underweight or even an increase in weight that is non-responsive to increase in dosage of diuretics
 - persistent symptoms despite optimum treatment of underlying condition(s)
 - the patient (or family/friends) asks for palliative care, chooses to cut down, suspend or even stop all further treatment; or wishes to focus on the quality of life
 - the patient says he/she does not have much longer to live.
- Talk with the patient regularly in order to evaluate the situation and the wishes of the patient and his/her family and friends. During the discussion, talk about the symptoms and how they affect physical, psychological, social and spiritual functioning. Examine the thoughts and wishes of the patient concerning the future and goals of treatment. If possible and acceptable, discuss the prognosis. If necessary, review the care plan based on this discussion.
- In the phase of disease-orientated palliation, focus on the benefits and burdens of treatment. Continue disease-orient-

tated treatment focused on the alleviation of symptoms for as long as possible.

- In palliative care in the terminal phase, be alert to burdensome symptoms and signals. Focus care primarily on comfort, the relief of suffering and the improvement of the quality of dying.
- Be attentive to the care of the bereaved family and friends after the death of the patient.

Advance care planning (ACP) in heart failure NYHA class III and IV

- Start discussing ACP early. For the motivating factors to hold these discussions, see previously mentioned criteria.
- Discuss current and expected symptoms in all domains of palliation, and where relevant and acceptable to the patient, also the following aspects:
- Individual life goals and the goals of care
 - view of life and cultural background
 - possibilities of palliative care
 - decisions on whether or not to have treatment
 - admission to hospital or an intensive care unit
 - place of care and dying
 - crisis situations (acute asphyxiation, refractory symptoms)
 - living will
 - lawful representation in the event of acute deterioration or loss of legal decision-making capacity
 - decisions concerning the end of life (including administration of fluids, food, antibiotics, resuscitation, turning off the shock function of an ICD, morphine for symptom relief (see guidelines on dyspnoea in the palliative phase), dialysis, palliative sedation, euthanasia, tissue donation, conscious stopping of eating and drinking)
 - resilience and burdens of family and friends and informal carers
 - wishes concerning the funeral
 - follow-up care
- Decide with the team who will be involved in these conversations (dependent on e.g. where the patient stays, where

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he/she is being treated and who the physician in charge is): cardiologist, heart failure nurse, geriatrician, GP, GP practice assistant, nurse practitioner, elderly care physician, consultant palliative care or physician for the mentally disabled. As needed, refer to colleague care givers, e.g. a psychologist, social care worker or mental/spiritual counsellor.

- Document the arrangements in the individual care plan and ensure that the other health care providers involved are aware of these arrangements. Give a copy of the arrangements that have been made to the patient.
- Repeat these discussions fairly regularly, check that the arrangements are still relevant and, if necessary, modify them. Document the changes in arrangements in the individual care plan and ensure that the other health care providers involved are aware of the changes.

Communication in heart failure NYHA class III and IV

How does the quality of communication about ACP between health care professionals and the patient and their family and friends contribute to the quality of life and death of patients with heart failure NYHA class III and IV? And how should this dialogue be carried out?

- Base discussions on ACP on the shared decision-making method, and check if the patient and his/her family and friends have understood the information.
- If necessary utilise:
 - The SPICT tool and app (www.spict.org.uk)
 - Plan the discussion with the help of Thoonsen's Proactive Care Planning Model.
- Draw the patient's attention to:
 - The patients' version of the ESC (European Society of Cardiology) website for patients: www.heartfailurematters.org. Chapter: Living with heart failure, text and video "Planning for the end of life".

- Use guides on palliative care for people with a non-western background.
- For further recommendations see Quality Framework for Palliative Care in the Netherlands (www.iknl.nl/framework-palliative-care).

Organisation of care in heart failure NYHA class III and IV

How does the organisation of care and associated communication between health care professionals contribute to the quality of life and death of patients with heart failure NYHA class III-IV?

- Ensure that it is always clear (at any moment of the disease) who the physician in charge is and who the central health-care professional is: cardiologist, heart failure nurse, other medical specialist (usually geriatrician or specialist in internal medicine), elderly care physician or GP. Discuss this and record it in the patient's case notes.
- For a patient who is under hospital's care:
 - Organise care in line with a heart failure outpatient clinic. In this, involve nurses and cardiologists specialised in heart failure as well as other disciplines, e.g. physiotherapist, dietician, social worker, psychologist. In geriatric patients with multimorbidity, treatment and support from - or in consultation with - a geriatrician or an internist specialised in care of the elderly is a good alternative. A nurse specialised in heart failure plays a central, coordinating role in the care around the patient and between all levels of health care, and is specially trained in this.
 - Ensure there are clear arrangements in place with primary care by means of verbal and written (including digital) communication.
 - Divide the care tasks among as few treating professionals as possible. Ensure clarity during the transfer (between care givers) of responsibility of being physician in charge.
- Document decisions on care to be implemented, or changes in care in an individual care plan.

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- Ensure timely transfer (both verbal and written) to primary care (home, nursing home or hospice). Ensure that the GP centre knows of these arrangements.
- If necessary in the home situation, make use of an expert in palliation, possibly as a member of a palliative team.
- For guidance and advice on palliative care:
www.spict.org.uk.

Treatment with medication in the three months prior to death from heart failure NYHA class III and IV

How do diuretics (eplerenone, spironolactone, furosemide, bumetanide, hydrochlorothiazide) influence the quality of life in patients with NYHA class III-IV heart failure in the three months prior to death? And when should these diuretics be stopped?

- Continue diuretics until oral intake is no longer possible, the patient no longer wishes to take medication and/or there is continuous hypotension (systolic blood pressure < 90 mmHg), despite the halving or discontinuing of other blood-pressure-lowering medication.
- Modify the dosage of diuretics contingent on the clinical condition of the patient (is there hypervolaemia, hypovolaemia, or euvolaemia?), weight and renal function. Aim for the lowest possible effective dosage. Halve the dosage of the diuretics when the systolic blood pressure < 90 mmHg and/or a deterioration in renal function (in particular if serum creatinine > 221 $\mu\text{mol/l}$ and clearance < 30 ml/min/1.73², if, in the event of renal failure, there is no hypervolaemia).
- In the event of continuous dyspnoea and oedema (consistent with heart failure and hypervolaemia) in patients who do not respond to an increase in the dosage of loop diuretics, combine loop diuretics with thiazide diuretics (preferably only temporarily). On doing this, check renal function and electrolytes (principally sodium and potassium).

- In the event of a variable state of hydration and associated symptoms, ask the patient to record their weight daily. Give instructions about fluid intake, modifying dosage of diuretics according to weight, and when to contact the doctor. Stop daily weighing in the event of severe deterioration, approaching terminal phase, and/or severe comorbidity.
- As a GP or home care nurse, contact the heart failure outpatient clinic at an early stage about the prescription of diuretics and modification of the dosage.
- In the event of repeated admission to hospital with heart failure: discuss with the heart failure team the continued IV administration of loop diuretics in the home situation. It is preferable to use a PICC line or sometimes a completely implantable system such as a Port-a-Cath (PAC) in patients who are resistant to oral diuretics, who responded well to IV treatment with diuretics in the hospital with clinical recovery and who are not in the terminal phase.

This intravenous therapy only takes place in a small group of patients following cardiological assessment. In patients under the care of a GP or elderly care physician.

- The goal is to continue oral treatment for as long as possible. The aim of treatment by continuous IV administration of loop diuretics is to alleviate the symptoms of heart failure as well as possible, so that (re)admission to hospital is unnecessary and the patient is able to die at home. When end of life approaches, discuss the benefits and disadvantages of continuous home IV treatment with the patient, his/her family and friends and the medical team. It is certainly not standard treatment, but it does offer a solution for a small group of patients to be able to die at home.

Criteria for intravenous treatment of heart failure via a PICC line:

- patient starts treatment in a hospital
- end-stage heart failure assessed by cardiologist during admission period
- history of regular admissions to hospital with heart failure, a minimum of twice in one year

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- good response to intravenous diuretics and resistant to oral diuretics
- the patient is motivated and able to give permission for intravenous treatment at home
- enough informal care or ability to cope
- proven therapy compliance and adequate insight into disease
- the patient must be fully aware of the goal of treatment: recovery cannot be expected, end-stage heart failure, preferably no hospital admission, treatment at home and the possibility of dying at home
- there must be no comorbidity that determines death or that contraindicates IV treatment.

How do beta blockers, ACE inhibitors and ARB's influence the quality of life in patients with NYHA class III-IV heart failure in the three months prior to death? And when should they be stopped?

- Continue to give beta blockers, ACE inhibitors and ARBs until the patient is no longer able to take the medication, the patient no longer wishes to take the medication, or in the case of ACE inhibitors and ARBs with serum creatinine > 221 $\mu\text{mol/l}$ and clearance < 30 ml/min/1.73m², or if adverse effects are negatively affecting quality of life.
- Regularly check the effects of beta blockers with reference to symptoms of heart failure, blood pressure, heart rate and adverse effects. In the event of symptomatic (orthostatic) hypotension (systolic < 90 mmHg) or bradycardia < 50/min, halve the dosage of the beta blocker. In the event of extreme fatigue or other adverse effects, consider lowering the dosage of beta blockers. Stopping beta blockers completely is also an option, depending on the situation and on the severity of the adverse effects. Check the effects of ACE inhibitors and ARBs regularly with reference to symptoms of heart failure, renal function and blood pressure. Halve the dosage of ACE inhibitors/ARBs in the event of symptomatic

orthostasis/hypotension and/or low blood pressure (systolic < 90 mm Hg) and/or > 50% increase in serum creatinine > 221 $\mu\text{mol/l}$, clearance < 30 ml/min/1.73m². Stop ACE inhibitor or ARB in the event of serum creatinine > 310 $\mu\text{mol/l}$ and/or a clearance of < 20 ml/min/1.73m².

- If it is necessary to discontinue medication: in principle, first stop the beta blocker (it should preferably be tapered off due to the risk of reflex tachycardia) and then the ACE inhibitor/ARBs. If the patient's symptoms are such that a beta blocker is more beneficial (e.g. in case of angina pectoris or dysrhythmia), then stop ACE inhibitor/ARBs first.

Netherlands Comprehensive Cancer Organisation

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Edition

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Februari 2018

