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The First Steps Taken to Implement Palliative Care in Advanced Heart Disease A Position Statement from Denmark

Vibeke Brogaard Hansen[1,2], Susanne Aagaard [2,12], Tove Bahn Vejlgaard[6,7], Jens Brock Johansen[2,3], Susanne Pedersen[2,4,5], Vivi Lindeborg Nielsen[13,19], Mette Asbjørn Neergaard[18,7], Gitte Ryom Salomonsen[12,13], Mai-Britt Guldin[17], Ida Gustafsson[2,16], Hans Eiskjær[2,12], Finn Gustafsson[2,11], Stine Gundtoft Roikjær[2,8,9], Betina Nørager[2,10], Henrik Larsen[7,14,15] and Ann-Dorthe Zwisler[2,8,9]

[1] Department of Cardiology, Lillebaelt Hospital Vejle, Denmark
[2] Danish Society of Cardiology (DCS)
[3]Department of Cardiology, Odense University Hospital, Denmark
[4]Department of Psychology, University of Southern Denmark, Denmark
[5] Department of Cardiology, Odense University Hospital, Denmark
[6]Palliative Care Unit, Lillebaelt Hospital Vejle, Denmark
[7]Danish Society of Palliative Medicine (DSPaM)
[8]Department of Medicine, Holbæk Hospital, Denmark
[9]Danish knowledge Centre for Rehabilitation and Palliative Care (REHPA)
[10]Congenital Heart Diseases, Rigshospitalet, Denmark
[11]Department of Cardiology, Rigshospitalet, Denmark
[12]Department of Heart Disease, Aarhus University Hospital, Denmark
[13] SIG-Palliation within Danish Society of Cardiovascular and Thoracic Surgery Nursing.
[14]Palliative Unit, Rigshospitalet, Denmrk
[15] Danish Muliti-disciplinary group for Cancer and Palliative Care (DMCG-PAL)
[16] Department of Cardiology, Hvidovre Hospital, Denmark
[17]Institute of Public Health – Research Unit for General practice, Aarhus University Hospital, Denmark
[18]Department of Oncology and Palliative Unit, Aarhus University Hospital, Denmark
[19]Department of Cardiology, Aalborg University Hospital, Denmark.

***Corresponding Author:** Vibeke Brogaard Hansen, Department of Cardiology, Beriderbakken 4, Lillebaelt Hospital Vejle, DK-7100 Vejle, Denmark, Phone + 4579496429; E-mail: vibeke.brogaard.hansen@rsyd.dk

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Abstract

Background: Patients with advanced heart failure are often hospitalized and have poorer prognosis than patients with several types of cancer. Furthermore, they have severe clinical symptoms alongside mental, social and spiritual struggles. According to the WHO, palliative care must be available for all patients with life-threatening diseases. However, present focus in daily practice is still world-wide on cancer patients.

Objective: To generate a national position paper on palliative care in advanced heart disease as the first step to implement palliative care in advanced heart failure, includes tools to identification of patients in need of palliative care and when care should be introduced in the clinical care trajectory. Furthermore, an objective was to describe how palliative care is recommended organized and distributed through multidisciplinary and multisectorial settings in Denmark.

Design and Methods: A task force was founded in the Danish Society of Cardiology Heart Failure working group, and the statement is prepared in collaboration with members from the following spe-

cialties: Danish Society of Palliative Medicine, Psychology, Intensive Care Units, Cardiac arrhythmia, Congenital Heart Diseases, Prevention and Rehabilitation, General Practice and Nursing. Due to major gaps in evidence the statement is based on smaller studies, clinical practice statements supplemented by knowledge from the cancer area.

Results: The current position paper is aligned with the European Society of Cardiology recommendation with focus on the relief of suffering starting in the early stage of the disease parallel to standard care as a supplement to life-prolonging treatment. The statement delivers practical hands-on guidance on clinical aspects and symptom management during the three stages of advanced heart disease. Further the statement focus on the importance of communication and lines out topics to be broached including deactivation of implantable cardioverter defibrillators. Regarding organizational strategies the statement recommends a targeted effort with use of assessment tools of high standard. The essence of a multidisciplinary and inter-sectoral collaboration is underlined.

Conclusion/discussion: Danish cardiologists supported by allied professions have acknowledged the importance of palliative care in advanced heart disease with the paper.

The position paper and clinical statement can deliver inspiration to other countries while waiting for the a joint statement from European and/or American palliative care Association.

Keywords: Palliative Care; Advanced Heart Disease; Multidisciplinary; Inter-Sectoral

List of Abbreviations: ACP: Advanced Care Planning; DCS: Danish Society of Cardiology; DSPaM: The Danish Association of Palliative Medicine; EACP: European Association of Palliative Care; ESC: European Society of Cardiology; GP: General Practitioner; GUCH: Congenital Heart defects; HADS: Hospital Anxiety and Depression Scale; ICD: Implanterbar Cardioverter Defibrillator; PHQ-9: Patient Health Questionnaire-9; PRN: Pro Re nata as Needed; SPIKES: Six-Step Protocol for Delivering Bad News; QOL: Quality of life; WHO: World Health Organization

INTRODUCTION

Patients with advanced heart failure are often hospitalized have a poorer prognosis than many cancer patients have and suffer severe physical symptoms. Moreover, they often suffer from anxiety and depression and struggle with social and spiritual issues. Despite these facts, when it comes to palliative care for patients with heart failure in Denmark as well as internationally, organization and knowledge are still lacking.

In 2011, the Danish health Authority developed recommendations for palliative care, calling on the professional societies, which treat patients with other diseases than cancer, to work out guidelines in this area [1]. In 2015, encouraged by the National Board of Health, the Danish Society of Cardiology (DCS) initiated a task force to develop a position statement to facilitate and optimize management of palliative care in advanced heart failure. The Danish Society of Cardiology (DCS) took on this task as one of the first professional societies in Denmark management non-malignant diseases. The aim was to conduct a position statement concerning palliative care and advanced heart disease, increase awareness of palliative care needs in non-malignant disease and inspire the process of implementation and organization of palliative care in advanced heart disease both nationally and internationally.

Background

The care and treatment for patients with advanced heart disease are managed broadly depending on the original disease; ischemia, heart valve-disease, cardiomyopathy, heart arrhythmia, Grown Ups with Congenital Heart defects (GUCH) and pulmonary hypertension. Chronic heart failure is the common end stage for all these groups with a mortality rate in line with the most severe cancer diagnoses.

Studies show correspondingly that these patients have a number of symptoms and unmet palliative needs of physical, psychological, social and spiritual nature. [2-7].

At the same time, evidence suggests that patients with advanced heart failure and their relatives do not have adequate access to the palliative care they need. [8, 9]

This applies particularly for grown-ups with congenital complex heart disease. Despite the fact that management of this disease is never with a curative intent, end-of-life discussions do not take place until the late palliative phase [10]. One of the barriers is the large prognostic uncertainty associated with these patients. Most of the patients, however, wish for an early and pro-active palliative effort including end-of-life discussions [11].

According to the World Health Organization (WHO) and the Danish Medical Authority, palliative care must be available for patients with life-threatening illness including heart failure [1, 12]. In practice however, the focus is on cancer patients nationally as well as internationally [13, 14]. In this paper, we focus on the process of developing a united position concerning palliative care and advanced heart disease in regards to the stages and prognostic chal

lenges of the disease, as well as recommendations of organization and management to promote palliative care in advanced heart disease nationally as well as internationally.

The Development Process

We established a task force group to carry out the work, in cooperation with similar specialized fields. The task force was founded in the DCS Heart Failure working group, and the statement is prepared in collaboration with members from the following specialties: Danish Society of Palliative Medicine, Psychology, Intensive Care Units, Cardiac arrhythmia, Congenital Heart Diseases, Prevention and Rehabilitation, General Practice and Nursing. Due to major gaps in evidence the statement is based on smaller studies, published meta-analysis, clinical practice statements supplemented by knowledge from the cancer area.

The objective was to:

- Establish a united opinion on palliative care and heart failure
- Improve the assessment of palliative needs and when they should be initiated
- Expand the knowledge of organization and management of palliative care on both interdisciplinary and inter-sectorial level.

Stages in Advanced Heart Disease and Prognostic Challenges

Chronic heart failure can be described as a condition influenced by a gradual development of symptoms. In the beginning, there are no or modest symptoms, but as time passes, the disease becomes refractory. Accordingly, the typical patient experiences a gradual worsening over time, with intermittent, acute decompensations, which often require hospitalizations [15-17]. All through the course of treatment, including the stable phase, the patients have an increased risk of sudden death (malignant arrhythmias) [15, 16, 18, 19]. Thus the prognostic challenge is different when it comes to heart patients compared to other life-threatening diseases as described by Murray (Figure 1) [17]. The unpredictability of the course of the disease may explain the limited palliative care for heart patients and the lack of evidence in the field [20, 21]. Continuing therapeutic optimism and prognostic paralysis may result in too late palliative care or no care at all for the individual heart patient [22]. European Society of Cardiology (ESC) recommends a model for palliative care which focuses systematically on the relief of suffering (physically, psychologically, socially and spiritually) beginning at the early stage of the disease parallel to standard care as a supplement to life-prolonging treatment [20]. Thus, make palliative care an integrated part of the disease-specific treatment. Table 1 depict the stages of heart failure and associated recommended palliative efforts.

Palliative Care in Advanced Heart Disease Symptomatic assessment

Symptoms such as fatigue, dyspnoea, nausea, pain, depression and anxiety are characteristic in patients with advanced heart disease (see Table 2), but there are minimal evidence concerning the treatment of these symptoms compared to other areas such as cancer [2-7, 23, 24]. Smaller studies suggest that focused palliative care for patients with advanced heart failure can achieve a favourable effect [25-28] but this needs to be demonstrated on a larger scale. Meanwhile, when it comes to clinical practice there is no evidence that the management of palliative symptoms experienced by heart failure patients should differ radically from the management of the symptoms experienced by cancer patients. Table 2 includes recommendations for the management of frequently occurring symptoms experienced by patients with advanced heart disease [29-31].

Discussions on Future Care and Treatment

Patients with heart failure need information on the expected development of their disease, prognosis, treatment and palliative care at all stages (see Table 1 and 2) [20, 29, 32-34]. At regular intervals, open, honest and empathic communication on the development of the disease is needed. There are several recommended models and tools available for this. The SPIKES-model has gained immense popularity when it comes to `breaking bad news´ [35]. "Advanced Care Planning" (ACP) is concerned with, but not limited to, conversations on the level of treatment and wishes at the end of life [36]. Table 3 shows an overview of topics to discuss in consultation with the patient and relatives.

Psychological reactions and spiritual aspects

Anxiety and depression have a prevalence of approximately 20 % in cardiac patients [20]. Due to the complexity and management of the disease, it may be difficult to identify anxiety and depression in the cardiac patient. Accordingly, a systematic screening using for example PHQ-9 or HADS [38] may be the best solution, even though these instruments are not validated when it comes to patients with chronic heart failure. Not only do the symptoms influence the patient´s quality of life (QOL) negatively, depression also reduces compliance and increases the risk for hospitalization and mortality independently from traditional risk factors [39]. There are several other treatment options than psychotropic (see Table 2) including cognitive behavioural therapy, psychologist sessions [40, 41] and conversations with

a priest, to name a few. This has not been explored in cardiac patients. Nothing indicates, however, that the treatment should be different for this patient group.

Deactivation of Implantable Cardioverter Defibrillator

In the terminal stage of life, it may not be appropriate that the implantable cardioverter defibrillator (ICD) is active. Accordingly, it is important to discuss the possibility of deactivation with patients and their relatives [42]. Patients with ICD have indicated that discussions on the issue of deactivation should take place before implantation and in case of decreased life expectancy [43]. The patients were also asked about their preferences for or against deactivation, in a hypothetical situation, and an association between a favourable attitude towards deactivation and the wish for a worthy death was found [43]. Table 4 highlights important issues to be discussed if the patient desires deactivation or if the professional believes that the time for deactivation has come.

The Last Days of Life in The Terminal Phase

When a patient is terminal and only have days or week left, the following steps should be taken:

- Reduce non-essential medication (discontinuation of vitamins, iron, statins and so on) and possibly change essential medication from oral to intravenous and subcutaneous administration.
- Discontinue systematic monitoring of vital signs, blood tests, intravenous fluids and so on [32, 44-46]
- Ensure that the patient and his or her relatives are informed about the changes made due to the imminent death and that they, as far as possible, understand – and agree upon - the care plan. Furthermore, identify other needs (i.e. are there any other family members who should to be involved?)
- Ensure future PRN prescriptions with recommendations of 'The Box of Security' Tryghedskassen (see Table 5)

Concerning the patients who wish to die at home, it is important to optimize palliative care in close collaboration with the patient´s general practitioner (GP), primary care nurse and, if possible, a local palliative team before discharge.

Relatives and Bereavement Support

The care for relatives and those left behind is an essential part of palliative care since the aim of the effort is to improve the quality of life of patients and their families facing the problems associated with life-threatening illness [12]. This, despite the fact that knowledge and practice when it comes to the involvement of relatives as a part of the general palliative care, and grief support in the aftermath of death, is limited within the field of heart failure [47].

Organization

The current organization of palliative care in Denmark is founded on:

- General level palliative care (provided by the parts of the health care system which do not have palliative care as their main task such as departments of cardiology, GPs and municipalities)
- Specialist level palliative care (provided by the parts of the health care system which have palliative care as their main task such as palliative teams, palliative departments and hospices)

Palliative care is thus characterized by being interdisciplinary and inter-sectorial, and a coherent effort requires a high level of organization and coordination. There is a continued need for clarification of substance and clinical practice for basic palliative care [48].

Recommendations for Targeted Service

For the purpose of targeted service based on individual needs assessment in patients with advanced heart disease we recommend the following:

1) The department specific services are gathered in one organizational unit for example the out-patient clinic (The heart failure clinic).
2) Establishment of an individual management teams consisting of the medical specialist responsible for the treatment and nurse and/or key persons in the cardiac medical ward.
3) Establishment of cooperation with other organizational units including the primary sector and palliative teams, including other relevant participants (psychologist, social worker, hospital priest, physiotherapist, occupational therapist, dietitian and so on) depending on local conditions and accessibility.
4) Scheduled regular meetings in order to discuss specific patient cases, exchange of experience and expansion of cooperation (Multidisciplinære Team-Konference, MDT).
5) Focus is put on education of health care professionals and development of their competences

Ethical and Legal Aspects

With a shift in treatment perspective from active treatment to palliative care, a number of ethical and legal aspects may arise [49]. On the other hand, ethical dilemmas also exist when medical treatment continues beyond the patient´s and the relatives´ wishes. We recommend involving the medical public health officer in specific cases of doubt.

Current Actions, Future Perspectives and Contribution to the International Scene

The boards of the European Association of Palliative Care (EAPC) and the Heart Failure Association (HFA) of the ESC have established at task force group to work out guidelines for palliative care for patients with advanced heart disease. This positions

statement from the Danish Society of Cardiology is the first step to acknowledging the importance of palliation for these patients.

Palliation should be a part of the specialist training and continuing medical education of cardiologists. At the same time, it is important that cardiac nurses and other healthcare professionals, who are in contact with heart patients, possess the right skills to manage palliative care. The goal being that evidence-based palliation becomes a natural part of cardiology care.

We at DCS have started this process in collaboration with The Danish Association of Palliative Medicine (DSPaM) and currently have had a supplementary course to specialists in cardiology and palliative medicine with the aim of uniting the two disciplines for the good of the heart failure patient in need of palliative care in the future. All the participated specialists represented from each of the four region in Denmark completed a workshop subsequently. A task jointly report based on their discussion with different experiences, organization, attitudes, ideas, regional opportunities and future agreements was made.

The coming years will reveal how palliative care is implemented in the clinical care trajectory to the benefit of patients and their relatives in Denmark.

There is a great international need for developing and researching palliative care for patients with advanced heart disease. Parallel to the build-up of evidence-based knowledge, focus should be on optimizing the implementation and organization of palliative care to patients with heart failure and their relatives and developing standards for a systematic assessment of palliative needs at all stages of the disease. Furthermore, the right services should be developed and implemented to support the particular needs for heart patients and their relatives. We recommend an establishment of quality assurance and evaluation of palliative care for instance through supplementary registration in already existing databases.

Finally, We believe that our national position paper and the described steps forward and after in Denmark in collaboration with the Danish Society of Palliative Medicine" is of general interest and not too linked to a local national reality concerning palliative care in advanced heart failure. Moreover, the described working process and the final statement might deliver inspiration to other countries while waiting for the work of a planned renewed taskforce with Heart Failure Association (HFA) of the European Society of Cardiology (ESC) and The European Association for Palliative Care (EAPC).

Tabel 1: Karakterisering af stadierne ved fremskreden hjertesygdom og anbefalet palliativ indsats samt kliniske indikatorer for Stadium 2.

Characteristics of the stages in progressive heart disease, recommended palliative care and clinical indicators in stage 2.

Stadium 1: Varetagelse af kronisk hjertesvigt (NYHA I-III) - Tidlig palliativ indsats
Stage 1: Management of Chronic Heart Failure (NYHA I-III) – Early Palliative Care
Aktiv behandling mhp. forlænget overlevelse og kontrol af symptomer.
Active treatment with the aim of prolonging life and controlling symptoms.
Patient og omsorgsperson (-er) uddannes om tilstanden, ætiologien, behandlingen og prognosen med henblik på god sygdomsindsigt og egenomsorg.
Patient and caregivers are educated on the condition, etiology, treatment and prognosis with the aim of improving self-management of symptoms.
Regelmæssig kontrol, følger nationale retningslinjer og lokale protokoller inkl. rehabilitering og fysisk træning.
Treatment is provided in accordance with the national guidelines and local protocols including rehabilitation and physical exercise.
Stadium 2: Støttende og palliativ behandling (NYHA III-IV) - Sen palliativ indsats
Stage 2: Supportive and Palliative Treatment (NYHA III-IV) – Late Palliative Care
Kliniske indikatorer:
Clinical indicators:
Tiltagende symptomatisk, tegn til begyndende multiorgansvigt samt genindlæggelser/perioder med dekompensation trods optimal behandling i henhold til guidelines
The patient becomes increasingly symptomatic with multiple admission to hospital because decompensation despite optimal treatment accordance to guidelines.
Høj alder og øvrig comorbiditet
High age and other comorbidities
Vurderet som ikke kandidat til transplantation eller LVAD
Heart transplantation and mechanical circulatory support are ruled out
Den antikongestive behandling tolereres ikke længere grundet hypotension og/eller skridende nyrefunktion
The congestive treatment is not tolerated because of hypotension and/or progressive renal impairment
Delir, mental ændring
Delir, changed mental status
Hyponatriæmi trods normohydrering
Hyponatriaemia despite normohydration
Begyndende kardiel kakeksi/lav albumin
Signs of cardiac cachexia/low albumin
Gentagen ICD terapi
Repeated ICD shocks
Aktiv, sygdomsrettet behandling reduceres.
Målet for pleje skifter til at opretholde optimal symptomkontrol og livskvalitet.
Active treatment is reduced, and the aim moves towards sustained optimal symptom control and quality of life.

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En professionel nøgleperson anbefales identificeret til at koordinere forløbet med henblik på optimal individualiseret pleje og kontakt med Hjertesvigtklinikken, sengeafsnittet, hjemmeplejen, egen læge og/eller Palliativ Team.
Identification of a key health professional is recommended to ensure optimal individualized continuity of care across multiple sectors and disciplines.
En helhedsorienteret, tværfaglig vurdering af patienten bør finde sted løbende samt vurdering af behandlingsniveauet i samråd med patient og pårørende (FPB). Optimalt i klinisk rolig fase og med kontinuert samtalepartner.
A holistic, multidisciplinary assessment of the patient and his needs should be conducted continuously in consultation with the patient and his relative. Preferably, with the same health professional and when their conditions is in a clinical stable phase.
Overvejelse om Terminalerklæring (LÆ165) og medicintilskud.
Declaration of terminal care (LÆ165) and financial support decisions should be considered.

Stadium 3: Terminal behandling og palliativ indsats
Stage 3: Terminal Treatment and Palliative Care
Patienten er uafvendeligt døende.
The patient is inevitably dying.
Hjertesvigtsbehandlingen skifter til symptomkontrol alene.
Heart failure treatment changes to symptom control only.
Afståelse for genoplivning ved hjertestop og intensiv behandlingsbehov skal dokumenteres.
A waiver of resuscitation in case of cardiac arrest as well as intensive treatment needs should be discussed and documented.
En integreret pleje til den døende anbefales varetaget efter individuelt behov med henblik på psykosocial støtte til patient og pårørende.
An integrated care plan should be devised with focus of the psychosocial support needs of the patient and their family or caregivers.
Ønske om døds- og plejested skal afdækkes.
The desired place of final care and death should be discussed and decided upon.

Indsatsen omfatter opfølgende støtte til de efterladte ved behov.
The care includes follow-up bereavement support as needed.

Tabel 2: Forslag til håndtering af hyppigt forekommende symptomer hos patienter med fremskreden hjertesygdom.

Possibe interventions for common symptoms in patients with advanced heart disease.

Symptom Symptom	Håndtering Possible intervention
Åndenød Shortness of breath	Revurdér/justér medicin (diuretika) Reevaluate medication (diuretics) Ilt (ved måltider, evt. permanent) Oxygen (or room air) during meals or permanent, fan, breathing training Bronkodilatorer Nebulized bronchodilators Nitroglycerin (ved akut indsættende åndenød) Nitrates Opioider Opiods Anxiolytika Benzodiazepines
	Ved jernmangel/anæmi, overvej iv Jern Anemia: Consider IV iron therapy Rollator Walking aids Kold luft på underansigtet (Se ovenfor) Fysisk træning Exercise training
Overhydrering/ødemer Swelling, edema	Loop-diuretika Loop-diuretics Kombination med thiazid. Metolazone ved nedsat nyrefunktion (Se nedenfor) Vasodilatorer Vasodilators Ved refraktær overhydrering med svære symptomer trods diuretika og vasodilatorer overvej inotropi. Diuretic resistance: Combine with thiazides and/or consider inotropes or hemofiltration Væskerestriktion Fluid restriction Saltrestriktion Salt restriction Sengeleje, eleveret fodgærde Increased rest/bedrest, reduction of physical activity
Svimmelhed Dizziness	Invaliderende svimmelhed: Seponér/reducér udløsende agens Reevaluate medication Behandle evt. arytmi Treat arythmia, if present Ved jernmangel/anæmi, overvej iv Jern Anemia: Consider IV iron therapy
Vægttab Weight loss	Fysioterapi, fysisk aktivitet, hvis muligt Exercise training Diætetisk vejledning Dietary guidance , nutritional supplements Kontrollér thyroideastatus Consider thyroid dysfunction
Kvalme, smagsforstyrrelser, nedsat appetit Nausea, loss of appetite	Revurdér/justér medicin Reevaluate medication Kontrollér biokemi (azotæminiveau, leverfunktion) Consider kidney and/or liver dysfunction Diætetisk vejledning Dietary guidance Ved medicinsk behandling kan forsøges Haloperidol, Lorazepam/Olanzapin, Metoclopramid eller Domperidon Consider Haloperidol, Metoclopramide, Lorazepam, Olanzepine or Domperidone Appetitstimulation (fx. små mængder alkohol, binyrebarkhormon)) Appetite stimulants (small amounts of alcohol, steroids)
Depression Depression	Undgå tricykliske antidepressiva. Avoid tricyclic antidepressants Sertralin, Agomelatin eller Citalopram kan anvendes. Endelig kan Mirtazapin med forsigtighed Selective serotonin reuptake inhibitors, sertralin Physical activity, psychological evaluation

Smerter Pain	Langtidsvirkende opioider (husk laksantia) Opiods Intensiveret antianginøs behandling Anginal pain: Anti-anginal medication and/or revascularization
”Fatique” Lack of energy, fatigue	Identifikation og behandling af potentielle sekundære årsager ex. Jernmangel/anæmi, infektion, dehydrering, elektrolytforstyrrelse, thyroidea sygdom, katabol tilstand, depression, søvnapnø etc. Identify and reat secondary causes (anemia, infection, sleep apnea etc) Fysisk træning Exercise training

Tabel 3: Emner, der kan berøres i samtalen om fremtidig pleje og behandling, afhængig af patientens sygdomsstadie.

Topics that can be used in a dialogue with the patient with respect to future care and treatment depending on the patient's disease stage.

- Sygdommens alvor og uhelbredelighed.
- The severity and incurability of the disease.
- Sygdommens mulige forløb (langsom forværring / pludselig død).
- Possible progression of the disease (slow deterioration / sudden death).
- Tilbud og støttemuligheder i forløbet, herunder også til pårørende.
- Options and possibilities of support during the process both for patients and their significant others.
- Behov for tilknytning af primær sygeplejerske.
- Need to assign a primary nurse.
- Behov for etablering af åben indlæggelse.
- Need to establish ”open hospitalization”.
- Mulighed for kontaktlæge og kontaktsygeplejerske på stamafdelingen.
- Possibility to have a contact physician and contact nurse at the ward.
- Fortsat tilknytning til Hjertesvigtklinikken.
- Continued affiliation with the Heart Failure Clinic.
- Egen læges rolle.
- The role of the general practitioner.
- Behov for henvisning til Palliativt Team.
- Need for referral to the Palliative Team.
- Livstestamente.
- Living will. ELLER Advance Healthcare Directive.
- Behandlingsniveau, hvis akut forværring.
- Treatment level in the event of acute deterioration.
- Undladelse af genoplivningsforsøg ved hjertestop.
- Do Not Resuscitate (DNR) order.
- Inaktivering af patientens Implanterbar Cardioverter Defibrillator (ICD).
- Deactivation of the patient's implantable cardioverter defibrillator (ICD).
- LÆ165 Ansøgning om socialmedicinsk sagsbehandling (såkaldt terminalerklæring, §122 Serviceloven).
- LÆ165 Application for socio-medical case management (so-called terminal declaration §122 Consolidation Act of Social Services).
- Ansøgning om terminaltilskud til medicin hos Lægemiddelstyrelsen (§148 Sundhedsloven).
- Application for subsidy for drugs towards end-of-life from the Danish Medicines Agency (§148 Danish Healthcare Act).
- Medicinsanering.
- Discontinuation of drugs.
- Mulighed for plejeorlov til nærtstående.
- Possibility of care leave for significant others.
- Behov for Hospiceindlæggelse.
- Need for hospice care.
- Præferencer for den sidste tid (hvor vil patienten helst opholde sig den sidste tid/dø).
- End-of-life preferences (where does the patient prefer to be towards end of life/to die)

Tabel 4: Emner, der bør berøres i samtale med patient / pårørende, hvis patienten har ønske om inaktivering af Implanterbar Cardioverter Defibrillator (ICD) anti-takykardi-terapi (ATP og stødterapi) i livets sidste fase eller, hvor professionelle skønner, at tidspunktet, hvor ICD-enheden bør slukkes nærmer sig.

Topics that can be used in a dialogue with the patient/significant other, if the patient wants the implantable cardioverter defibrillator (ICD) anti-tachycardia-therapy (ATP and shock therapy) function to be deactivated towards end-of-life, or if health care professionals deem that it is time to deactivate the ICD.

- Sygdommens alvor og uhelbredelighed.
- The severity and incurability of the disease.
- Afsøge om patient/pårørende kender til mulighed for inaktivering af ICD-enheden.
- Examine whether patient/significant other is aware of the possibility of deactivating the ICD.
- Dialog omkring inaktivering af ICD-enheden: Dialogue about deactivation of the ICD:
  - Inaktivering vil ikke føre til død.
  - Deactivation will not lead to death.
  - Inaktivering af ICD-enhedens shock funktion vil ikke inaktivere pacefunktionen, hvis patient har pacemaker.
  - Deactivation of the shock function of the ICD will not deactivate the pacing function, if the patient has a pacemaker.
  - Inaktivering er ikke smertefuldt og vil ikke gøre døden mere smertefuld.
  - Deactivation is not painful and will not make death more painful.
  - ICD shocks i livets sidste fase kan være ineffektive, smertefulde og lede til angst hos både patient som pårørende.
  - ICD shocks towards end-of-life can be ineffective, painful and lead to anxiety in both patients and significant others.
  - Inaktivering kan være med til at sikre en fredfyldt død og undgåelse af unødige shocks.
  - Deactivation can help ensure a peaceful death and the avoidance of unnecessary shocks.
  - Hvis patientens omstændigheder ændrer sig, kan ICD-enheden re-aktiveres.
  - If the patient's circumstances change, the ICD can be re-activated.
- Sikring af at patient / pårørende forstår, hvad inaktivering af ICD-enheden betyder samt konsekvensen heraf.
- Ensure that the patient/significant other understands what deactivation of the ICD means and the consequences
- Spørge ind til patientens og pårørendes ønsker.

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• Ask about the preferences of patients and significant others. • Beslutning om eventuel inaktivering af ICD-enheden, og hvornår det skal ske. • Decision to deactivate the ICD and when it should take place. - Informeret samtykke med patient (med tilstedeværelse af eventuelle pårørende). - Informed consent from patient (with presence of significant others if relevant). - Beslutning noteres i patient journal. - Make a note of the decision in the patient's electronic health record. - Patientens praktiserende læge adviseres om beslutning. - Inform the patient's general practitioner about the decision.

Tabel 5: Indhold af Tryghedskassen og standard forslag til ordinationer.

Content of the "Tryghedskassen"* and standard dosage suggestions

*"Just in case" (JIC) treatment box = contains medicine for the terminal patient who can no longer take p.o. medicine.

Det officielle ansvar for Tryghedskassens indhold ligger hos DMCG-PAL. Produceres på Glostrup og Skanderborg Apotek, hvorfra den kan distribueres til hele landet med tilhørende utensilier og informationsmateriale.

DMCG-PAL is formally responsibile for the content of the "Tryghedskassen". It is produced by and distributed from Glostrup Pharmacy and Skanderborg Pharmacy.

Inj Morfin 20 mg/ml, 2,5- 5 mg i.v/s.c. p.n. uden max mod smerter og åndenød Inj. Morphine 20 mg/ml, 2,5 -5 mg iv/s.c. p.n., without maximum, for pain and dyspnea. (Morfin ordineres efter udregning i forhold til patientens aktuelle opiod døgndosis) (Morphine is prescribed after calculation of the patient's factual dosage for the last 24 hours). Inj. Midazolam 1 mg/ml, 1-3 mg i.v/ s.c. p.n. uden max mod angst, uro og søvnløshed Inj. Midazolam 1m/ml, 1-3mg iv/s.c. p.n., without maximum, for anxiety, unease and sleeplessness. Inj. Serenase 5 mg/ml, 0,5-1 mg i.v/s.c. p.n., max 6 gange pr døgn mod kvalme, vrangforestillinger, begyndende delir Inj. Haloperidole 5 mg/ ml, 0,5-1mg iv/s.c p.n., maximum x 6/24 hours, for nausea, delusion and incipient delirium. Inj. Furix 10 mg/ml, 10- 40 mg i.v/ s.c. p.n. uden max ved ødem og mistanke om lungestase Inj Furosemide 10mg/ml, 10-40mg iv/s.c. p.n., without maximum, for pulmonary edema. Inj. Buscopan 20 mg/ml, 20 mg iv/s.c p.n., max 120 mg døgn mod sekretraslen Inj. Hyoscinbotylbromid 20mg/ml, 20mg iv/sc pn., maximum 120mg/24 hours, for death rattle.

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Recommended Reading

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