Cardiac Supportive Palliative Care Guidance (CS-PCG)

Professional Resource

Cardiac Supportive Palliative Care Guidance (CS-PCG)

This supportive and palliative care guidance has been designed to support cardiac professionals to feel confident about caring for people living with and dying from advanced heart failure. The guidance encourages seamless integration of supportive and palliative care principles, alongside evidence based heart failure and comorbidity therapies from diagnosis onwards.

All too often palliative care is associated with end of life. This guide encourages professionals to adopt a different perspective, by thinking about supportive palliative care as an essential intervention in its own right; supporting patients who are experiencing change associated with an uncertain trajectory, to live as well as possible. End of life care although very important, is a small part of supportive palliative care intervention.

In doing so, people living with and dying from advancing heart failure, should be able to experience high quality individualised care and support, from diagnosis through to end of life and bereavement.

Heart Failure is a progressive, disabling and life limiting condition, which is the final common pathway for almost all cardiovascular disease.

Perception and prognostic challenges often lead to a delayed recognition that decline and subsequent death is a possibility by clinicians, patients and families. Opportunities to enable a collaborative, person centred, cardiac supportive and palliative care approach, is often too late or missed completely.

Invariably this leads to patients and families experiencing high symptom burden, emotional distress, poor quality of life, inappropriate goals of care, and recurrent prolonged and often terminal hospital admissions.

Adopting an approach that enables early identification, comprehensive assessment, anticipatory care planning and cohesive working, can support persons living with and dying from advanced heart failure to experience the right care, in the right place at the right time.

Key Message: Active heart failure care should always run parallel to supportive palliative care. One does not stop for the other to commence.

Cardiac Supportive Palliative Care Core Components

Underpinned by meaningful conversations, appraisal of understanding and management of realistic expectations from diagnosis onwards.

1
Early Identification

2
Comprehensive Assessment

3
Anticipatory Care Planning

4
Cohesive Working

Communication and Co-Ordination

NYHA I/IV

Optimal Therapy

Unmet Needs

Cardiological and Person Centredness

Evolving meaningful conversations and anticipatory care planning

Partnership working across different care settings

Inspiring Person Centredness and Creating Change

What Matters,
Who Matters,
When it Matters
Approach

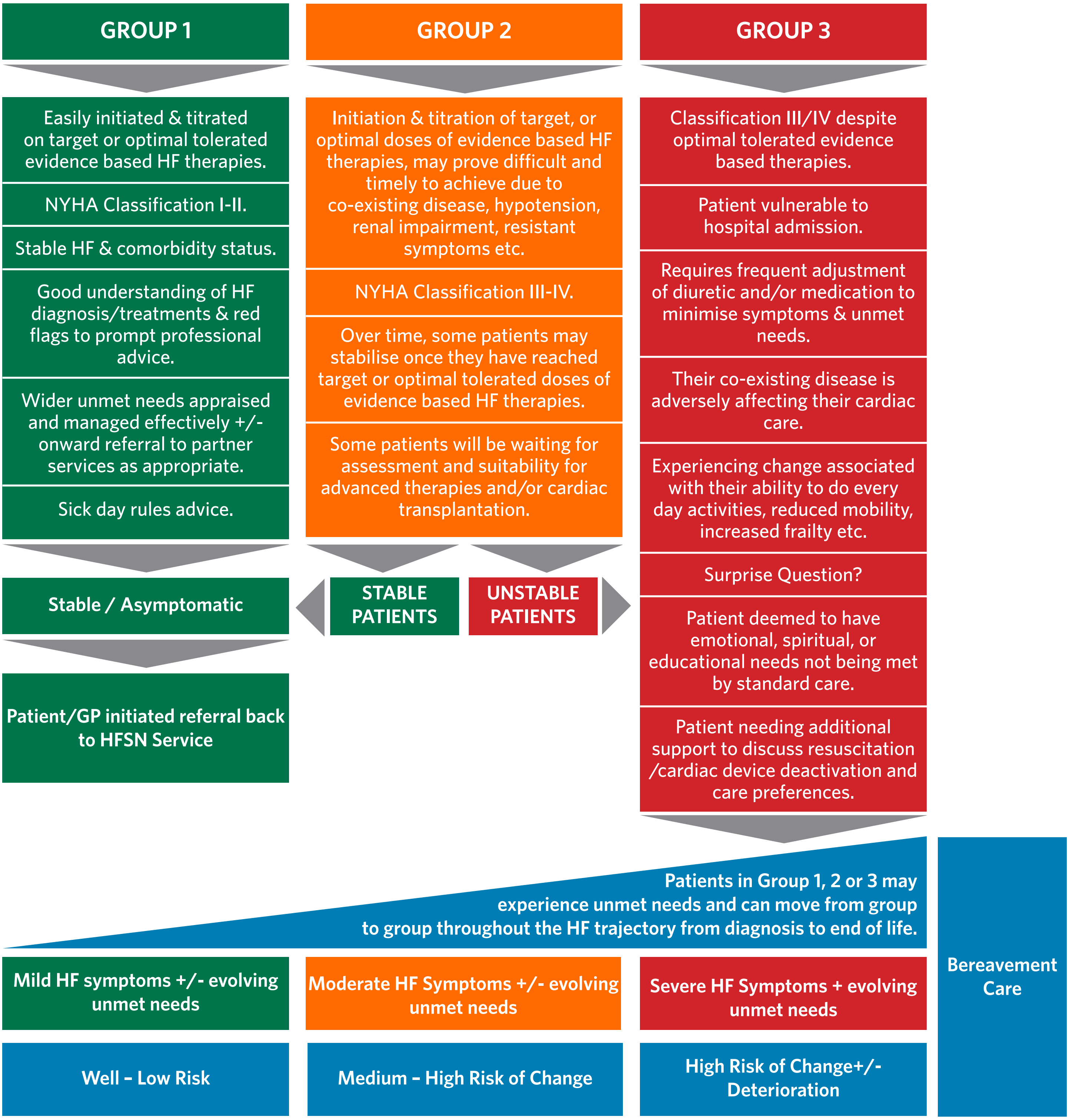
Underpinned by Realistic Medicine Principles

Right **Care,**
Right **Place,**
Right **Time**

Key Message: Adopting an approach that enables early identification, comprehensive assessment, anticipatory care planning and cohesive working, can support persons living with and dying from advanced heart failure to experience the right care, in the right place at the right time.

Core Component 1:

Early Identification of patients to one of the 3 groups below may help to identify evolving unmet needs.



GROUP 1

- Easily initiated & titrated on target or optimal tolerated evidence based HF therapies.
- NYHA Classification I-II.
- Stable HF & comorbidity status.
- Good understanding of HF diagnosis/treatments & red flags to prompt professional advice.
- Wider unmet needs appraised and managed effectively +/- onward referral to partner services as appropriate.
- Sick day rules advice.

Stable / Asymptomatic

Patient/GP initiated referral back to HFSN Service

GROUP 2

- Initiation & titration of target, or optimal doses of evidence based HF therapies, may prove difficult and timely to achieve due to co-existing disease, hypotension, renal impairment, resistant symptoms etc.
- NYHA Classification III-IV.
- Over time, some patients may stabilise once they have reached target or optimal tolerated doses of evidence based HF therapies.
- Some patients will be waiting for assessment and suitability for advanced therapies and/or cardiac transplantation.

STABLE PATIENTS

UNSTABLE PATIENTS

GROUP 3

- Classification III/IV despite optimal tolerated evidence based therapies.
- Patient vulnerable to hospital admission.
- Requires frequent adjustment of diuretic and/or medication to minimise symptoms & unmet needs.
- Their co-existing disease is adversely affecting their cardiac care.
- Experiencing change associated with their ability to do every day activities, reduced mobility, increased frailty etc.
- Surprise Question?
- Patient deemed to have emotional, spiritual, or educational needs not being met by standard care.
- Patient needing additional support to discuss resuscitation /cardiac device deactivation and care preferences.

Patients in Group 1, 2 or 3 may experience unmet needs and can move from group to group throughout the HF trajectory from diagnosis to end of life.

Group 1	Group 2	Group 3	
Mild HF symptoms +/- evolving unmet needs	**Moderate HF Symptoms +/- evolving unmet needs**	**Severe HF Symptoms + evolving unmet needs**	**Bereavement Care**
Well - Low Risk	**Medium - High Risk of Change**	**High Risk of Change+/- Deterioration**	

Key Message: Remember patients can move from group to group throughout the disease trajectory.

Early Identification of High Risk Patients with Unmet Needs

Integrating the principles of supportive cardiac and palliative care for patients in group 1 to group 3, provides an opportunity for patients to have their evolving unmet care needs addressed. This should encourage a seamless, timely and realistic approach, which needs to be supported with meaningful discussion throughout.

Any patients in Group 1,2 or 3 may be experiencing unmet needs. Patients in Group 3 are most likely to be at highest risk of deterioration and most likely to be characterised as:
NYHA Classification III/IV despite being on optimal tolerated evidence based HF therapies.

- Vulnerable to hospital admission and/or frequent review by the HFSN.
- Require frequent adjustment of diuretic/adjunct therapy to minimise symptoms.
- Have co-existing disease affecting further optimisation of their cardiac care.
- Experiencing change associated with their ability to do every day activities such as getting washed and dressed.
- Find it more difficult to get out and about or to mobilise around the house.
- Surprise Question (would you be surprised if the patient died within the next 12 months)?
- Those deemed to have emotional/spiritual, or educational needs not being met by standard care.
- Those needing additional support to discuss as appropriate resuscitation/cardiac deactivation and care preferences.

Not all of the criteria cited above needs to be evident. Use this information to guide the identification of the evolving unmet needs, associated with the movement of patients from stable to high risk as appropriate. Remember the NYHA Classification can be a subjective measurement and for patients who are immobile, may not be a true reflection of their symptoms.

Key Message: Palliative care does not mean giving up or hastening death. It should be considered with all other active care. If done well the experience of the patient, carers and professionals is a very positive one.

Core Component 2:

Comprehensive Assessment

The comprehensive assessment should include appraisal of:

- The patient and families should have a good understanding of their condition, the current situation and their expectations for now and for the future; the ‘what matters to you’ questionnaire supports this.
- An assessment of a patients cardiological and comorbidity status, in partnership with their lead clinician, to determine appropriate and realistic goals of care and care preferences.
- A comprehensive assessment of physical, psychological, social and occupational, carer and spiritual unmet needs. Using validated assessment tools can evidence subtle changes associated with these domains.
- Using a validated carer strain assessment tool can evidence requirements for additional support to enhance living well and safely at home. REMEMBER carer strain may also be experienced by patients if they are supporting their spouse or other dependents.
- Benefit entitlement to ensure this is maximised. Referral to partner agencies may be indicated to ensure that the patient is in receipt of any illness benefit, reduced heating, council tax and utility tariffs as appropriate. Many patients will meet the criteria for a mobility blue badge, pendant alarm, sensory impairment and carer support services etc.

Key Message: Changes may not always be disease specific and may be more related to a reducing mobility, function or increasing frailty which adversely impacts on everyday lives. Comprehensive assessment should always be regarded as an evolving process that requires regular evaluation of unmet needs.

Core Component 3:

Anticipatory Care Planning

Adopting a "What, Why, Who and When" approach to anticipatory care planning, can be used to encourage meaningful conversation about what a person would like, what they don't like and how best to care for them during periods of change. This might be associated with deteriorating health, personal care and/or personal circumstances. This timely approach supports the creation of individualised, evolving, anticipatory care plans (ACP). Sometimes referred to as advance care planning.

The ACP should be created in partnership with the patient, carer and key professionals involved in their care. It should reflect evolving discussion about:

- Patient and carer understanding of how things are now and their expectations going forward.
- Current cardiological and comorbidity status.
- Realistic goals of care.
- Care preferences: appropriate goals of care, place of care and place of death. Place of care and death may differ e.g. home may be the preferred place of care with hospital, care home or hospice being the preferred place of death.
- Cardio-Pulmonary Resuscitation Status.
- Timely deactivation of cardiac devices if appropriate (ICD or CRT-D).
- Admission avoidance guidance to support the community and/or out of hours' team, in minimising symptoms which have previously triggered a hospital admission.

The ACP should be shared with all key clinicians involved with the patient's care and a copy should be given to the patient with their consent to be kept at home. Remember this should not be a one time conversation and the preferred care wishes may change in response to changing physical, psychological, social and or carer needs.

Key Message: The ACP is an evolving, meaningful discussion between the patient, their carer and key clinician which is often the heart failure nurse. This discussion should focus on ensuring that everyone is able to live well, knowing that their wishes have been heard and will be respectfully implemented in response to inevitable change.

Core Component 4:

Cohesive Working

Acknowledging the unique contribution of the wider professional team is absolutely essential to enable the provision of high quality supportive cardiac and palliative care, for persons living with and dying from advancing heart failure. The opportunity for seamless collaboration and cross fertilisation of knowledge, skills, expertise and peer support is invaluable.

It is important to acknowledge that the majority of patients will require **generalist** palliative care support, which can be provided in partnership with the community care team consisting of the General Practitioner, District Nurse, Pharmacist and all other Health and Social Care Providers as appropriate.

Patients who have **complex** unmet cardiac palliative care needs should be referred to the local specialist palliative care team, to enable cohesive working to manage ongoing needs as appropriate. This may include referral to hospice day therapies, community joint visits in the patient's home or inpatient services. It is important to remember that hospices are not just for end of life care. Many patients and carers benefit from a short term inpatient or outpatient intervention by specialist palliative care which is focused on supporting them to live well throughout their illness trajectory.

Additional members of the wider professional team may include the dietician, occupational therapist, cardiac physiologist, physiotherapist, speech and language therapist, spiritual director etc.

Key Message: Professionals may require peer support with the assessment and management of complex unmet patient needs. Specialist and generalist palliative care providers can have a key role in supporting cardiac professionals to develop confidence and competence during informal clinical shadowing, joint visits or during MDT discussions on a patient-by-patient basis. Equally, cardiac professionals can provide invaluable cardiac specific support and knowledge to specialist and generalist palliative care professionals.

Communication and Co-ordination

Meaningful dialogue between a professional and patient should be naturally occurring, and should begin at diagnosis and continue onwards. As professionals we often perceive conversations associated with change and deterioration as being difficult. In doing so we may defer or put off having the conversation until it is too late.

Effective communication underpins all core components of a supportive cardiac and palliative care approach. The following are some examples of how meaningful conversations can be initiated from diagnosis onwards. It is not possible to list every type of conversation or suggested response.

The Ask-Tell-Ask is a collaborative communication method which enables professionals to use open ended questions to appraise the patient and carers understanding, for now and for the future. This appraisal is vital to ensure that the patient and carers understanding is good, prior to sharing additional information. This approach also provides an opportunity to identify and manage the patient and carers expectations realistically.

Using the Ask-Tell-Ask model of communication can be helpful to initiate meaningful dialogue for all individuals regardless of their heart failure and general wellbeing status. Individuals in group one are potentially at lower risk of deterioration and subsequent death, others in group two or three may have an intermediate or high risk of deterioration and death. Nonetheless, individuals across all three groups may wish to disclose information about their concerns, fears, expectations and hopes for now and in the future.

Always be honest with people and don’t use euphemisms. If you don’t know the answer to an individual’s specific question, clarify you have understood what they are asking, and make sure you arrange for someone else to be able to talk to them on another occasion (if you can join this conversation, it is invaluable not only to you but demonstrates your support to the patient/family).

“Meaningful discussion between a professional and a patient in anticipation of inevitable change should be naturally occurring and should begin from diagnosis onwards. Please think about these discussions as meaningful and not difficult. If we perceive them to be difficult we will avoid having them” Yvonne Millerick

Illness Understanding, Prognosis and Information Needs

Beginning the consultation: this might be at a first appointment with a newly diagnosed patient, or a subsequent patient review. A good starting point after formal introductions, is to invite your patient to disclose from their perspective why they are here and what their expectations are from you. You may wish to go on to ask some or all of the following:

ASK: It would be good to get a sense of what your understanding is of your diagnosis and how this affects your day to day activities.

TELL: Tailoring information, confirm that their understanding of their diagnosis and related symptoms is good, or that you might have a different understanding, and ask if they would like you to share this.

ASK: Is there anything else about your heart failure condition, its treatment and or symptoms that you would like to learn more about?

TELL: Some people like to know a lot of information about their illness, what their quality of life will be like in the future and how their disease might progress.

ASK: Is this something you would like to know more about today?

TELL: It can be difficult to predict what will happen with your illness, I hope you will be well. Some people with heart failure can become less well and less able to do every day activities over time, or become sick quite quickly.

ASK: Is this something you have been thinking about? Would you like to discuss this in more detail today?

TELL: I have given you a lot of information, would you like me to talk more about this today or go over anything I have said so far (gives people space to stop the conversation).

Key Message: When probing about what patients/carers might like to know, some may indicate they do not want to discuss prognostic type information: it might be helpful to check why, paradoxically it may help you to find a way to discuss this at a later review. Importantly not all people are ready to talk about this now, the conversation being raised may help them move to this at a later date. Some people never wish to know anything, or discuss anything, or may have others they prefer to talk to. Always leave an invitation for them to ask you again if they would like to.

Responding to Direct Questions About Diagnosis, Prognosis and or Advancing Disease

Individuals or their families on hearing the words heart failure may say something like … “this sounds serious”… “am I/are they going to die from this ” or “might I die suddenly”

ASK: Is this something you have been thinking or worrying about? (their response might help shape how you can respond)

TELL: Gently say … heart failure is a serious diagnosis (give people a few moments to gather their thoughts). You might go on to say, I am happy to talk more about this with you and also share information about how we can support you to live well. If this is a new patient who is hearing the diagnosis for the first time, explain that whilst heart failure is a progressive illness, we know that many patients respond well to evidenced-based treatments and regular monitoring. Explain that the focus at all times is on making sure they receive and experience the best evidenced care possible to enable them to live well. If the patient has advancing disease as described in group 2 or 3 you may wish to follow the suggestions in the anticipatory care planning section.

Acknowledging people’s emotions can really support them when discussing prognosis or deterioration … saying something like … I can see this is something you were not expecting or, I am sorry this looks like it has been tough for you to hear and giving them space to talk without interruption, helps to develop honesty and trust.

ASK: If they would like you to speak to someone else on their behalf, about what you have discussed or if they would like an appointment with their family to talk about this further.

Key Message: Balancing honesty and hope is really important: remember you are a messenger; you are not giving them this illness by talking honestly about it. Although evidenced-based treatment has significantly improved prognosis for people with HF over the years not all people will respond well. While some live for years, others may not be so lucky. Living well and having the opportunity to inform care preferences should happen regardless of where the patient is on the illness trajectory.

Anticipatory Care Planning

An uncertain trajectory is often experienced by patients with heart failure, when periods of stability and living well are often punctuated with episodes of deterioration, that sadly many patients will not recover from. It is important to acknowledge that not all deterioration is disease specific and may be more associated with increasing frailty, reducing mobility and a loss of capacity. Nonetheless these triggers can occur acutely or progress, and usually lead to the patient becoming less well and less able to function on a day-to-day basis. Uncertainty is often used as a barrier, instead of an opportunity by professionals to engage in meaningful dialogue with patients and their carers throughout the illness trajectory.

ASK: You have been telling me that how you are feeling now has changed. Is this something that you wish to chat more about?

TELL: If the patient does not wish to chat more about this whilst it is important to respect this, it can be useful to go on and ask

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ASK: If you could help me understand your thoughts about why you would rather not discuss this today, it may help me know more about how to discuss future concerns with you.

TELL: If the patient does wish to chat more about it you can begin by saying something like; I know you have been feeling unwell over the last few months, and/or I know this because you have required frequent medication changes to help reduce symptoms and/or you have experienced several hospital admissions and/or required several home visits. I have also noticed that the time between you feeling well and becoming unwell is getting shorter.

ASK: Is this something that you have also noticed and would you like to talk more about this?

TELL: We have acknowledged today that how you are feeling and what you are able to do and not do is not as good as it was several months ago

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ASK: Is there anything about this change that you are concerned about for now, or for the future?
TELL: Some patients may respond by saying that they are worried about how this will affect their family, or they are concerned about becoming more dependent on their family if they become less able to do things for themselves. Others may not want a discussion at this time. We should respect this and allow the patient to consent to continuing with the discussion or postponing it to another day.

For patients and carers who do wish to discuss this more, you may want to ...

Anticipatory Care Planning Continued ...

ASK: Would it be helpful to talk about what we can do to support you and your family if you were to become more unwell?

TELL: You might want to add something like: it is helpful to know what is important to you and your family in advance of this happening to you. This may involve discussion about what you would like, and not like to happen to you.

ASK: Do you understand what I mean by this?

TELL: You may want to say something like: for some patients and their families, it is important to know what treatments and support will be offered to them, for others it is important to know that being cared for at home, or admission to hospital or other care environments will be options offered to them, such as (hospice, care home etc) if they become more unwell.

ASK: Is this something you have thought about and would like to talk about now?

TELL: In the same way that it is helpful to know what you would like to happen to you when you become more unwell, some people find it helpful to also know what they should expect not to happen when they become more unwell.

ASK: Is this something you have thought about? If so, would you like to talk more about this?

Cardio-Pulmonary Resuscitation

ASK: Would it be helpful to talk about what we can do to support you and your family if you were to become more unwell?

TELL: We have already acknowledged that becoming more unwell can mean that your heart is weakening. For some this can mean slowing down, becoming more housebound and unable to manage shopping or light housework. For others it can mean personal care activities are not possible without support from family and/or homecare services. It is important to recognise that as our heart begins to weaken it often leads to a reduction in our daily function, the ability to do even minimal activities and can often result in increased symptoms of breathlessness, fatigue, chest discomfort and leg swelling. Whilst we can always help to make you feel better by treating your symptoms, there are some aspects of medical care that we would not be able to do without causing more harm. It is often helpful to discuss what we mean by this with your clinical team.

ASK: Would you like to know more about this? A possible response might be … I am not sure what you mean by this.

ASK: Have you ever considered what would happen to you if your heart stopped? A possible response might be … 'if my time is up it's up, I don't want any heroics!'. For others they may ask what do you mean by this?

TELL: You may have seen on the television, when the heart and breathing stops it means that the person has died. With some people the heart and breathing can be restarted again with mouth to mouth respirations, chest compressions and/or a shock to the heart. It is important to know that this is only effective for a small number of people. For people with advancing disease such as advanced heart failure it is not normally successful, and is likely to leave you in much poorer health than you are currently experiencing. For many this can be very distressing and cause you more harm than good.

ASK: Is this something that you would like to talk more about?

Key Message: Discussions about "do not attempt" cardiopulmonary resuscitation (DNACPR) should always be discussed with the wider team to determine if CPR is indeed a realistic treatment option, which for a small number of patients it can be. The conversation should always commence with an appraisal of the person's understanding of what we mean by cardiopulmonary resuscitation. It is vital that people understand that a DNACPR decision, does not exclude all other treatment options which have the potential to improve the patient's clinical outcomes. For example antibiotics for infection, further adjustment of cardiac medications and an active cardiac device.

Deactivation of Cardiac Devices

Discussion about cardiac devices and timely deactivation, should ideally commence at implantation and continue throughout the illness trajectory. It is helpful if patient's expectations of their device remains realistic during periods of good health and wellbeing, as well as when their health irreversibly declines. A good starting point is always to begin with appraising their understanding of the device and the different therapies that there device offers.

For some It may be helpful to ask when their device last fired and how that made them feel. For many, this is described as a distressing experience which they live in constant fear of experiencing again. It may be helpful to acknowledge that this experience sounds both frightening and distressing. You may want to continue the conversation by simply asking:

ASK: Is this something you would want to discuss further.

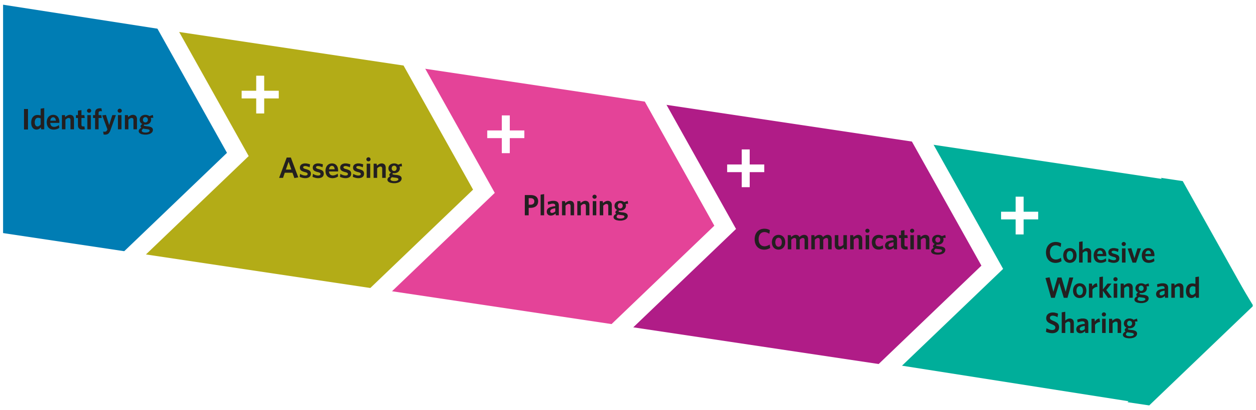
TELL: Reassure the patient and their family that a decision to deactivate the shocking therapy of the cardiac device, would be discussed in partnership with the wider clinical team to ensure appropriate and timely decision making. Advise the patient and their family that the other device therapies that help to minimise symptons will remain active.

Key Message: Deactivating the device does not mean giving up or hastening death. It is important to ensure patient's and carer's expectations are realistic. There should be a good understanding that an active device will not stop the heart from weakening. It is important to discuss that there maybe a time when the burden of leaving the shocking therapy of the device active, may prove to be more harmful for some patients.

It is feasible to have an active cardiac device in the context of a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) directive. Managing expectations and engaging with meaningful conversation with patients, carers and the wider professional team about cardiac devices can ensure appropriate and timely deactivation.

An Ideal Approach for the Modern Health Care System

Integrating the Cardiac Supportive Palliative Care Core Components is an ideal approach for the modern health care system as it promotes: maximum shared knowledge, increased awareness and minimal uncertainty;



= Living Well+ Dignified Death + Positive Legacy

Key Message: The Cardiac Supportive Palliative Care Guidance, promotes meaningful conversations and cohesive working. Integrating the core components of early identification, comprehensive assessment and anticipatory care planning, enables patients to live and die well, supports families and leaves behind a positive legacy.

Symptom Management Considerations

Comprehensive assessment of individual symptoms which are commonly associated with advancing heart failure, is essential to inform appropriate and effective management plans. Identification and treatment of an underlying reversible cause, is crucial to manage symptoms effectively. It is helpful for the patient to share the impact that their symptoms have on their day-to-day life, and factors that worsen or minimise symptoms. It is also important to acknowledge that symptoms originate from a blend of pathophysiological, physical, psychological and existential changes associated with hope, culture and spiritual beliefs. Managing patient and family expectations is important, particularly if initial treatments require escalation to manage symptoms more effectively. Not all symptoms can be eradicated, therefore patients and their families should be aware of this from the onset. Using validated symptom assessment tools to evidence the scale of symptom burden, and response to treatment strategies, is beneficial for patients, carers and professionals. If patients describe lots of symptoms, it may be helpful to acknowledge the scale of the symptom burden, and encourage the patient to think about which one or two symptoms they would like you to focus on today, as a starting point. This helps to manage the expectations of both patient and the professional, and ensures that not too many changes are made at the same time.

Common symptoms associated with advancing heart failure may include breathlessness, fatigue, cough, oedema, generalised or specific cardiac or comorbidity pain, nausea, anorexia, constipation, diarrhoea, increased micturition, poor quality sleep, depression, anxiety, tissue viability issues, dizziness, fear, reduced confidence, pruritus, dry mouth and deterioration in general function. When undertaking a comprehensive assessment of each symptom it is helpful to exclude reversible causes, ascertain onset and duration, as well as factors that help to minimise the symptom.

Most symptoms can be minimised with a combination of pharmacological and non-pharmacological intervention. Local and national pallitive care guidelines and collaborative working with the wider professional team including specialist pallative care can support you to manage symptoms effectively.

Examples of Validated Assessment Tools

1. **Palliative Care Outcome Scale (POS)**
   Schildmann EK, Groeneveld EI, Denzel J, Brown A, Bernhardt F, Bailey K, Guo P, Ramsenthaler C, Lovell N, Higginson IJ, Bausewein C, Murtagh FEM (2016) Discovering the hidden benefits of cognitive interviewing in two languages: the first phase of a validation study of the Integrated Palliative care Outcome Scale. Palliat Med 30(6):599–610. https://doi.org/10.1177/0269216315608348
2. **Supportive and Palliative Care Indicators Tool (SPICT)**
   Highet G, Crawford D, Murray SA, Boyd K (2014) Development and evaluation of the supportive and palliative care indicators tool (SPICT): a mixed-methods study. BMJ Support Palliat Care 4(3): 285–290. https://doi.org/10.1136/bmjspcare-2013-000488
3. **Needs Assessment Tool: Progressive Disease - Heart Failure (NAT:PD-HF)**
   Waller A, Girgis A, Davidson PM, Newton PJ, Lecathelinais C, MacDonald PS et al (2013) Facilitating needs-based support and palliative care for people with chronic heart failure: preliminary evidence for the acceptability, inter-rater reliability, and validity of a needs assessment tool. J Pain Symptom Manag 45(5):912–925. https://doi.org/10.1016/j.jpainsymman.2012.05.009
4. **Kansas City Cardiomyopathy Questionnaire (KCCQ)**
   Green CP, Porter CB, Bresnahan DR, Spertus JA. Development and evaluation of the Kansas City Cardiomyopathy Questionnaire: a new health status measure for heart failure. J Am Coll Cardiol. 2000 Apr;35(5):1245-55. [PMID: 10758967]
5. **Carer Support Needs Assessment Tool (CSNAT)**
   Ewing G and Grande G (2012) Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: A qualitative study. Journal of Palliative Medicine 27 (3) 244-256 https://doi.org/10.1177/0269216312440607

Acknowledgements

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Endorsements

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