

HFCNS Meeting

Feb 7th 2019

What we know

- LVSD (HFrEF) drug optimisation within 3 /12 of diagnosis
- 80% of pts still diagnosed in hospital setting
- HF specialist care in IP setting reduces mortality and readmissions
- Specialist review within 10 days of discharge / Home visits
- Education / supportive role of HF CNS
- Care is costly / need to utilise resources
- Pharmacist support esp in co morbidities / Polypharmacy
- Palliative care not only reduces symptoms but improves QoL and LoF
- 3% of us say they are happy to die in hospital – but > 50% of us do
- Numbers of ICD implants are increasing
- Psycho social support is paramount
- HFpEF- the Cinderella - good diuretic and co morbidity management is key

What's new

HF meeting Nov 2018

- Patient feedback - Pivotal role of HF CNS ands want a key Nurse
- National Confidential Enquiry into Patient Outcome and Death (NCEPOD) Supports addition of PC as core component of HF MDT team
- PC study presented - the Bromley St Christopher's project

NICE guidelines 2018

- Key point of contact / Navigator (outlined as HFCNS)
 - Prognosis, sudden death, misconceptions about risk, frank discussions about uncertainty in predicting course of HF and continually update and info as patient needs
 - Advanced care discussions to be made by Specialist HF team
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- Ensure the Lynda Blue's inspiring and mammoth achievements for improving the role of the HF Nurse and the care of HF patient receives goes from strength to strength
 - Role of home visiting remains pivotal

Recent steps in Advanced HF care

- Increasing number of DNAR discussions
- Bromley St Christopher's project
- Pacing physiologists are deactivating more ICDs - need our support
- New ICD deactivation guidelines
- ICD support group (very well attended) including EOL discussions
- ICD book updated - includes paragraph on deactivation / emotional aspects
- Increasing number of patients assessed
- Combined Specialist nurse reviews – HFNS / PC NS
- Some HF CNS involved in EOL and ICD discussions but appears variable

Bi-ventricular Defibrillator / Cardiac Resynchronization Therapy (CRT-D)

and a recent check with the arrhythmia nurse if you are unclear.
You must inform the DVLA if you have a shock, as you will not be able to drive for six months following this.

Deactivating the ICD.

At the end of life, regardless of the cause of death, these devices need deactivating. This means 'turning off' the shocking function of the defibrillator so that you are not unnecessarily 'shocked' in the last minutes of life. You would continue to get the therapeutic benefits from the bi-v pacing but would no longer have life-prolonging therapy in the event of a ventricular tachyarrhythmia. Turning off the ICD will not cause death.

Psychological support for patients with ICDs

People adjust to changes differently. Many people function like their normal selves right after the procedure and others take a little while to adjust. It is not uncommon to feel anxious or low in mood due to worries about the device. Most people get used to it and report an improved quality of life knowing it is there to prevent sudden death. You may find comfort from attending an ICD support group where you connect and gain support from fellow patients as well as healthcare professionals. If your anxiety or low mood persists, there is effective psychological support that we can refer you to.

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Clinical Guidance

Deactivating Implantable Cardioverter Defibrillators (ICDs)

Summary

This document provides guidance on the management of implantable cardioverter defibrillators (ICDs) towards the end of life and after death.

Document Detail	
Document Type	Clinical Guideline
Document name	Deactivating Implantable Cardioverter Defibrillators (ICDs)
Document location	GTCJ Clinical Guidance Database
Version	1.0
Effective from	January 2019
Review date	January 2022
Owner	Dr Jessica Webb, Consultant in Cardiology
Author(s)	Jessica Webb, Parisha Khan, Jessica Peplow, Carys Barton, Julia deCoursey, Lindsay Ip, Shaheen Khan
Approved by, date	
Superseded documents	Guidelines for deactivating implantable cardioverter defibrillators (ICDs) in people nearing the end of their life. March 2013 South London Cardiovascular and Stroke network
Related documents	
Keywords	Implantable Cardioverter Defibrillator, ICD, magnet, reprogramming, end of life, dying, heart failure, palliative care
Relevant external law, regulation, standards	<ul style="list-style-type: none"> • DH (2008) End of life care strategy: promoting high quality care for all adults at the end of their life • Mental Capacity Act 2005

Heart Failure Specialist Nurse Competency Framework



HFSN Name.....

Band.....

Date commenced framework.....

Academic achievements

Below is a record of your academic achievements to support your level 3 and 4 core competencies which are essential and desirable to support your practice as a HFSN.

There are spaces left for you to complete with related modules you may have completed to support your competencies.

Module/Course	Date Completed	Institute/Education	Provider
Clinical Assessment			
Heart Failure			
Non-medical Prescribing			
Advanced Communication Skills			
Palliative Care			
Cognitive Behaviour Training			

Palliative and End of Life Care					
Competencies	Level 1	Level 2	Level 3	Level 4	
	Under supervision	With minimal assistance	Without assistance	Competent to assess others	
Able to identify patients who may require palliative/end of life care and know how to implement the local pathway					
Discusses individual cases with the MDT involved in the patient's care i.e. GP, Cardiologist, Community Matron and family/carers to determine when a palliative approach is appropriate					
Able to identify or act as a key care co-ordinator who has a good understanding of the need for a holistic MDT approach to the patient's management					
Assesses the individual family/carers needs for information and involvement in decision making					
Able to provide psychological support and refers to other agencies/services required					
Able to explore and discuss patients' wishes on preferred place of care at end of life and to co-ordinate their care to support this					
Able to identify social needs and liaise with social services as required					
Able to identify drugs/therapies that are no longer appropriate					
Able to discuss with the patient and plan for deactivation of devices as necessary					
Demonstrates knowledge and ability to apply symptom control and advice to patients, family/carers and other HCPs involved in the patient's management					

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Heart Failure Specialist Nurse Service Operational Procedures Acute and Community Setting



What is current practice

Over last month / 6 months

1. Discussion about guarded prognosis and treatment options
2. Place and preference of care at end of life
3. Discussions re ceilings of care – what you do **not** want
4. Discussion about role of ICD and how /why it is turned off at end of life
5. Discussion about deactivating ICD in near future
6. Discussion and completed paperwork and arranged ICD deactivation with team
7. How many have had DNAR discussions
8. Feel it is your role to talk about EoL care
9. Feel adequately trained to do this
10. Have completed / attended Advanced Communication skills
11. Did the Advanced Communication skills course increase d/w re EOL / PPC discussions
12. Did you document the discussion in clinic letter
13. Have discussed / asked GP to stop medication that is no longer appropriate
14. Taken a case to MDT for discussion re advanced care planning

PMI	Group	Type	Score	Description	Referral	Alert
P661851	Heart Failure Service Nurse led	MLHFQ	73 / 105	Physical domain: 28 Emotional domain: 23		
				1. causing swelling in your ankles or legs?	0	
				2. making you sit or lie down to rest during the day?	2	
				3. making your walking about or climbing stairs difficult?	4	
				4. making your working around the house or yard difficult?	3	
				5. making your going places away from home difficult?	3	
				6. making your sleeping well at night difficult?	4	
				7. making your relating to or doing things with your friends or family difficult?	4	
				8. making your working to earn a living difficult?	3	
				9. making your recreational pastimes, sports or hobbies difficult?	5	
				10. making your sexual activities difficult?	4	
				11. making you eat less of the foods you like?	3	
				12. making you short of breath?	4	
				13. making you tired, fatigued, or low on energy?	4	
				14. making you stay in a hospital?	4	
				15. costing you money for medical care?	0	
				16. giving you side effects from treatments?	3	
				17. making you feel you are a burden to your family or friends?	3	
				18. making you feel a loss of self-control in your life?	5	
				19. making you worry?	5	
				20. making it difficult for you to concentrate or remember things?	5	
				21. making you feel depressed?	5	

PMI	Group	Type	Score	Description	Referral	Alert
P661851	Heart Failure Service Nurse led	PHQ9	26 / 27	Probable Major Depression	Follow risk assessment guide; contact liaison psychiatry for advice if needed. Consider urgent referral to 3DLC. Notify GP	Suicidal Thoughts
				1) Little interest or pleasure in doing things?	3 (Nearly every day)	
				2) Feeling down, depressed, or hopeless?	3 (Nearly every day)	
				3) Trouble falling or staying asleep, or sleeping too much?	3 (Nearly every day)	
				4) Feeling tired or having little energy?	3 (Nearly every day)	
				5) Poor appetite or overeating?	2 (More than half the days)	
				6) Feeling bad about yourself - or that you are a failure or have let yourself or your family down?	3 (Nearly every day)	
				7) Trouble concentrating on things, such as reading the newspaper or watching television?	3 (Nearly every day)	
				8) Moving or speaking so slowly that other people have noticed? Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual?	3 (Nearly every day)	
				9) Over the last two weeks have you had thoughts that you would be better off dead or of hurting yourself in some way?	3 (Nearly every day)	
				10) You have indicated that you have some of the problems on this questionnaire. How difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?	Somewhat difficult	

PMI	Group	Type	Score	Description	Referral	Alert
P661851	Heart Failure Service Nurse led	GAD7	21 / 21	Significant levels of anxiety which would be worth exploring further	Refer to 3DLC if anxiety is affecting management of or related to heart failure. Otherwise refer to IAPT. Notify GP	
				1) Feeling nervous, anxious or on edge?	3 (Nearly every day)	
				2) Not being able to stop or control worrying?	3 (Nearly every day)	
				3) Worrying too much about different things?	3 (Nearly every day)	

MINNESOTA LIVING WITH HEART FAILURE® QUESTIONNAIRE

Please consider completing this Questionnaire as it helps guide management and care. The following questions ask how much your heart failure (heart condition) affected your life during the past month (4 weeks). After each question, circle the 0, 1, 2, 3, 4 or 5 to show how much your life was affected. If a question does not apply to you, circle the 0 after that question.

Did your heart failure prevent you from living as you wanted during the past month (4 weeks) by -

	No	Very Little			Very Much
1. causing swelling in your ankles or legs?	0	1	2	3	4 5
2. making you sit or lie down to rest during the day?	0	1	2	3	4 5
3. making your walking about or climbing stairs difficult?	0	1	2	3	4 5
4. making your working around the house or yard difficult?	0	1	2	3	4 5
5. making your going places away from home difficult?	0	1	2	3	4 5
6. making your sleeping well at night difficult?	0	1	2	3	4 5
7. making your relating to or doing things with your friends or family difficult?	0	1	2	3	4 5
8. making your working to earn a living difficult?	0	1	2	3	4 5
9. making your recreational pastimes, sports or hobbies difficult?	0	1	2	3	4 5
10. making your sexual activities difficult?	0	1	2	3	4 5
11. making you eat less of the foods you like?	0	1	2	3	4 5
12. making you short of breath?	0	1	2	3	4 5
13. making you tired, fatigued, or low on energy?	0	1	2	3	4 5
14. making you stay in a hospital?	0	1	2	3	4 5
15. costing you money for medical care?	0	1	2	3	4 5
16. giving you side effects from treatments?	0	1	2	3	4 5
17. making you feel you are a burden to your family or friends?	0	1	2	3	4 5
18. making you feel a loss of self-control in your life?	0	1	2	3	4 5
19. making you worry?	0	1	2	3	4 5
20. making it difficult for you to concentrate or remember things?	0	1	2	3	4 5
21. making you feel depressed?	0	1	2	3	4 5

OK as he is does not want help

income support

Issues raised with ICD deactivations / PC referrals

Common issues emerging with ICD deactivation

- Ongoing issues with getting paperwork / ICD deactivation forms in timely manner
- Lack of coordination between teams
- Lack of understanding on various levels
- Increasing number of DNAR discussions but no ICD discussion
- ATP v ICD shock deactivations

- Patients refereed - seen but not followed up 'as no current PC needs'
- Patients declining referrals

- **We need to look at what /support /training for all teams involved and more joint working**
- **We need to have the discussions as get P Care input in good time for final stage planning**

- **Nearly everyone feels better after wards having had frank conversations as it helps patient and family to be same page. We need to ensure we do waste this valuable time**

Next steps

ICD group - to look at last 6 – 8 cases you were involved in

- Pacing team / HF CNS / Referrer meeting to at seamless running of ICD deactivations
- Parisha Khan
- Hannah Simmons
- Julia deCoursey
- Fiona Hodson
- ? Reshma
- Missed opportunity in hospital setting
- Paper work and who is responsible
- Issues understanding urgency
- Evening / weekend hours
- Joint working – buddy system
- Process

- **The only thing I fear now if life – I am looking for happy death**
- **Good letting go**
- **Allow family to get to the same place at same time - the and if fine**
- **We will all die – 3 % say we do not want to die in hospital – but > 50% of us do**
- **Need time to prepare and allow us time to make plan for death**
- **Nearly everyone feels better after wards having had frank conversations as it helps family / us not to waste valuable time**
- **All docs / nurses will be looking after people who are approaching end of life - all need skills - it is not pass it on to another team**
- **Place for living**
- **Getting the maximum out of what remains**
- **Most pts in hospices are outpatients**
- **Hospice is a place to live well— not a place to die**
- **Celebration of life and living it to the full**
- **Early PC actually improved prognosis so we need to ensure that PC does not think it is trade off**

- Increasing evidence that having PC actually live longer in addition to better symptom control
- Recurring ED visits give false hope and don't help through this part of life
- We need to prep for death - complete , say goodbyes,
- Just to have meds because they are available but does not mean it is right thing to do
- Docs / nurses do what we know best and to continue in pursuit of our needs - easier to do things that are active as opposed to offering PC
- Pts come to an acceptance if encouraged or were allowed to by others - do not keep doing scans / tests
- PC provision early within an admission to hospital is more cost effective than adding in later
- Hospice - care more for needs of pt as opposed to Hospital where it is all too hectic -
- Talks about doing things that are important to you over the years - make living life begin when diagnosed
- Improve symptoms so that patient can do the things they would like to do.