

Case Study

EOLC

JACINTA GODDEN

OUTREACH HEART FUNCTION NURSE SPECIALIST

GREAT WESTERN HOSPITALS TRUST

Introduction

- ▶ This case study describes the end of life experience for a person with a CRTD.
- ▶ As her care turned to palliation, her wishes were not to have the ICD component of the device deactivated.
- ▶ The case study aims to give an illustration of the issues and challenges faced at end of life by the patient and her family and also those of the healthcare team in caring for them.

Background

- ▶ 60 year old lady (Jane)
- ▶ Severe LVSD and severe mitral regurgitation
- ▶ CRT-D in place
- ▶ Referred to community heart failure service approximately 2 years before her death
- ▶ Medicines management 'balancing act ' of up-titrating evidence based first and second line treatments, AF control, fluid management in presence of hypotension and fluctuating renal function
- ▶ Poor prognosis and increasingly symptomatic heart failure
- ▶ Assessments for mitra-clip and heart transplant but was not accepted for either

Social Situation

- ▶ Happily married, living with husband.
- ▶ Worked as furniture restorer but became increasingly unable to continue.
- ▶ Daughter, mental health problems, sectioned twice, drug and ETOH abuse. Tense relationship at times.
- ▶ Safeguarding issues for her baby granddaughter – gained custody of her aged 2, and lived with her grandparents for last 2 years of Jane's life.
- ▶ One older sister – prone to over involvement in family issues
- ▶ Enjoyed the love and support of a small group of close female friends
- ▶ No particular spiritual beliefs

Patient wishes in care planning

- ▶ Always wanted active treatment.
- ▶ Did not want to discuss or consider ICD deactivation as her condition deteriorated.
- ▶ Focus of priority for her care planning was on wellbeing of her grandchild and rehabilitation of her daughter
- ▶ Prognosis and outlook frankly discussed by Cardiologist pre-referral for mitral clip and later, heart transplantation
- ▶ Declined early referral to specialist palliative care services
- ▶ Husband supported her wishes
- ▶ Cardiologist, GP and HFSN kept in close liaison to manage care and offer support

Approaching the end of life

- ▶ A week before Jane died , sustained wrist fracture in a fall
- ▶ Rapidly lost mobility and independence.
- ▶ GP called in the palliative care team with her consent
- ▶ Heart failure symptoms stable and not distressed
- ▶ Continued to refuse to agree to DNAR and deactivation of ICD.
- ▶ Husband supported this.
- ▶ On the day she died, a new palliative care nurse visited early afternoon
- ▶ Jane very weak, little fluid intake, but conscious and wanting to engage with visitors.

End of life

- ▶ The palliative care nurse (PCN) felt Jane's death was imminent.
- ▶ Husband requested HFSN speak to Jane re deactivation of ICD.
- ▶ Jane asked if she was dying - it was gently explained she was.
- ▶ Jane asked for all visitors and family to leave wanting only to be left that evening with her husband and granddaughter.
- ▶ She agreed to ICD deactivation only if she lost consciousness.
- ▶ Ensuing activity- urgent DNAR order requested by PCN. HFSN returned to deliver magnet for PCN to apply as per Jane's wishes. Jane wanted to be left alone with her family until the PCN returned 2 hours later.

End of life

- ▶ In that time, Jane passed away with her husband beside her and her granddaughter sleeping in the next room
- ▶ HFSN visited early the next morning.
- ▶ Her husband described Jane's death as ' the way she wanted it' and 'very peaceful'- except for '2 sudden and short 'convulsions' she had just before she died'

Some reflections

- ▶ The challenge of reconciling Jane's right to autonomous decision-making against the healthcare team's concerns about a painful/distressing death.
- ▶ The challenges of managing unrealistic expectations/misconceptions about ICD deactivation at the end of life
- ▶ The benefit of a fresh set of eyes in recognising the transition to the terminal stages of life.
- ▶ The logistical difficulties of both planned and emergency deactivation in the community for areas that have poor access to deactivation services
- ▶ How could we the MDT have done things better?

Conclusion

- ▶ Jane's death as was she wanted it, at home, alone with her husband and grandchild and in control of her care until the very end.
- ▶ She had listened to the risks to her of possible painful defibrillation in the dying stages of life and had decided to take that risk.
- ▶ There is still work to be done in healthcare to provide robust systems for emergency and planned deactivation of ICDs in the community.