Modern Choice – A Means to an End

Jill Nicholls, Heart Failure Specialist Nurse
Dr Katharine Thompson, Palliative Medicine Consultant
Dr David Rooke, Consultant in Old Age Psychiatry
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The Patient Story

Jill Nicholls
Heart Failure Specialist Nurse
June 2017

History

- Medical history:
  - 74 year old Male
  - Ischaemic heart disease
  - Myocardial Infarction x 4 (first 1998)
  - Coronary Artery Bypass Graft
  - Angina
  - Peripheral vascular disease – Fem Pop bypass 2013
  - Diabetes & neuropathy
  - Back pain resulting in Decompression Discectomy 2013
  - Smoker

Support Network

- Widowed 2012
- Moved up to Scotland
- Sister and niece living nearby
- Good friend visits every morning
- Daughter – Stirling and living with MS
- Lives in a caravan
- Dog

Overview

- Emergency admission post orthopaedic surgery with decompensation of heart failure – oedema, dyspnoea
- Referred to HFNLS August 2013
- High burden of heart failure signs and symptoms – NYHA Class IV
- Cardiac Resynchronisation Therapy requested by consultant at that time
- Three different consultants involved

Clinical Management

- Clinical assessment/ PMH review
- Information re HF and self management
- Medication options explored – BP & dizziness
- Pain clinic for neuropathic pain
- Bereaved – low mood ?depressive element
- CRTD inserted January 2014 - ICD initially, second part 2/12 for difficult CRT leads
- Consent in clinic / CIU on day

Patient Response

- Heart failure symptoms stabilised
- Neuropathic pain remain main complaint
- Optimised HF meds / diuretic regime
- NHYA Class II
- Discharged from HFNLS Jan 2015

Re-referral

- Brief 24 hr admission Oct 2015 with decompensating HF due to LVSD and chest infection, struggling at home post discharge and had stopped all medication
- Admitted to community hospital – DAMA
- Re-referred to HFNLS Oct 2015
- Home visiting

Assessment Impressions

- Very low in mood
- Clear overall deterioration noted
- ‘Does not want to live anymore’
- Defibrillator activity +++
- Pain +++
- Sleeping max 1.5hrs, despite sedation
- DNACPR document via GP
- Discussion re medication management for symptoms and ? for defibrillator deactivation

Management

- Fluid congestion managed with medication
- Device report confirmed 11 episodes of VF (treated) in September 2015
- Device settings adjusted and medication altered to regulate rhythm activity
- Discussed with Consultant Cardiologist and Palliative Care colleagues re patient request to deactivate defibrillator (‘D’ part of CRTD) component

Colleague Partnership

- As HF nurse, concern that unmanaged symptom burden may be contributing to decision making
- HF referral to Palliative Care specifically to assess
  - Insomnia
  - Depression
  - Severe pain
  - Wish to deactivate therapy currently being used

Palliative Perspective

Dr Katharine Thompson
Consultant in Palliative Medicine
June 2017

Referral - Background

Male

74yrs old

- LV Systolic Dysfunction
- IHD
- Mitral Regurgitation
- CTR-D
- Diabetes
- Peripheral Neuropathy
- Depression

- Poor quality of life due to:
  - Pain
  - Low mood, worse since wife died 3yrs ago

Referral - Question

- Device activating several times per month
  - 11 times in preceding month
- Patient wishes device deactivation
- Referral:
  - Could symptom control improve quality of life?
  - Is request for deactivation reasonable?

Assessment

- Initially seen alone:

- Adamant and insistent that he wishes deactivation of device
- Wants to be dead - has done since his bereavement
- Denies suicidal ideation or intent – would not put daughter through it
- Device is in direct contravention of his clear wishes

Why did he consent to it?

- He “did not know” purpose or implications of device
- Accepted it at time of acute illness as was told he needed it
- “Would not have accepted it even then” if he had understood

- ACP discussion prompted understanding
- Has since persistently and urgently requested deactivation

“Nothing will change my mind”

- Denies that low mood and pain contribute to his view
- Willing to accept:
  - Increase in Duloxetine
  - Trial of appropriate analgesia
  - Regular attendance at day care

- Seen again with daughter
- Lives in Stirling but close and visits frequently
- She feels he still has QoL but he chooses to withdraw
- She is categorically against device deactivation
- He repeatedly tells her she will have to accept it
- She will not support decision but would accept it

Incongruous

- Physically well at present – PS 80%
- No awareness of device activation
- Makes good eye contact and engaged in conversation

- Appears to be enjoying day care
- Making friendships
- Emotionally engaged and empathic with daughter

My perspective

- 74 year old patient, PS 80%
- Multiple co-morbidities
- CTR-D activating frequently

- Articulate, empathic and engaged
- Persistent and resolute wish for device deactivation
- Will humour me in attempt at symptom control and social engagement...in order to promote his agenda

- Although uncomfortable, **I feel he has capacity to make this decision**

Next Steps

- Formal assessment of patient's capacity to decide to withdraw treatment

- In the context of:
  - Depression
  - Chronic pain
  - Frequency of device activation

- Referred to psychiatry via phone and letter
- Agreed psychiatry would refer to CLO post assessment
- Initiated email contact between all parties
- Informed Clinical Lead

Role of the Psychiatrist

Dr David Rooke
Consultant Psychiatrist
June 2017

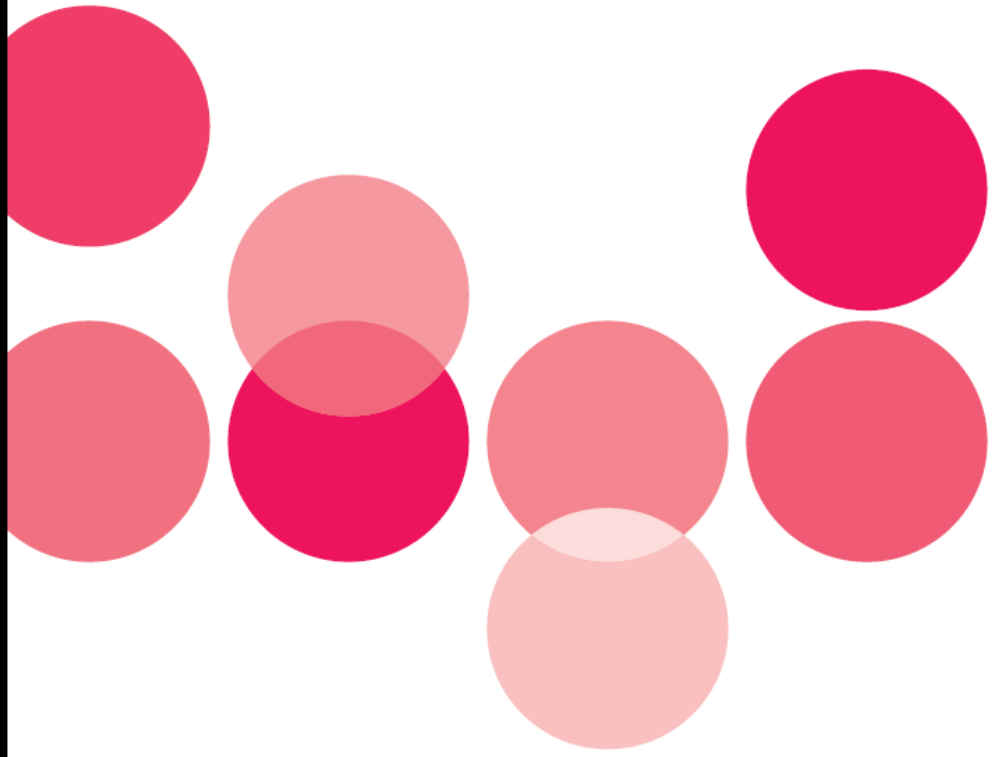
Role of the Psychiatrist

- Assessment of mental capacity
- Assessment of mental health
- The ethical dilemma...

ADULTS WITH INCAPACITY
(SCOTLAND) ACT 2000

Communication and Assessing Capacity

A guide for social work and health care staff



The Scottish Government, Edinburgh 2008

Assessment of Mental Capacity

- There is no all purpose test for incapacity. The test depends on the decision to be taken... or task to be done. The principles of least restrictive alternatives and maximising the person's capacity underline the importance of not making blanket assessments of incapacity and recognising any residual capacity the adult has.

Assessment of Mental Capacity

- There is a legal presumption of capacity for any adult (aged 16 years or older)
- Capacity is task specific and seldom global
- Imprudence does not equal incapacity
- All staff (especially those that know the adult well) should be involved in decisions regarding capacity.
- Medical staff and Section 22 approved psychiatrists are often involved if legal reports are required

Assessment of Mental Capacity

- **Legislative framework is the Adults with Incapacity (Scotland) Act 2000**
- Does the person have a **mental disorder** (which includes mental illness, learning disability, dementia and acquired brain injury), or a **severe communication difficulty** because of a physical disability (such as a stoke or severe sensory impairment)?
- If so, has it made the person unable to make the decision or decisions in hand?

Assessment of Mental Capacity

For the purposes of the 2000 Act an adult cannot make decision(s) if they are incapable of:

- Acting; or
- Making decision; or
- Communicating decisions; or
- Understanding decisions; or
- Retaining the memory of decisions

Assessment of Mental Health

- Is there evidence of a major mental disorder (such as depression, mania, psychosis, cognitive impairment) that can be demonstrated as having a direct effect on decision making ability?

- Our patient had a well documented mild to moderate depressive illness that contributed to a somewhat negative outlook but he did not show evidence of disorder of mind / thought to suggest that it had a major contribution to his decision making

Ethical Issues

- It is easy to over focus on the ethical issues in such a case and often if the assessor works through relevant legal frameworks and local / national protocols the solution becomes clearer

- If an adult does not meet criteria for inclusion into the major legal frameworks (Mental Health Act, Adults With Incapacity Act, Adult Support and Protection) and retains capacity they are legally able to refuse treatment

The Role of the Central Legal Office

Lorna McPhail
Senior Solicitor
Central Legal Office, Edinburgh
June 2017

Who we are

- Established 1948
- Over 50 solicitors
  - Litigation
  - Commercial Contracts
  - Commercial Property
- Our clients - Health Boards and Special Boards

What we do

- Provide specialist legal advice in relation to all areas of law that are relevant to the Health Service in Scotland

What we provide

The Litigation teams provide advice and representation in relation to:

- Clinical negligence
- Employee accidents
- Fatal Accident Inquiries
- Mental Health
- Practitioner Services

Response to general queries

- Information Governance
- Consent
- Withdrawal of treatment

First Contact from the Client
21 December 2015

- Conversation with consultant psychiatrist who had been approached to provide an opinion in relation to capacity
- Patient had implantable cardioverter defibrillator
- Alarm triggered by abnormal heart rhythms 7-9 times a month
- Patient wished device removed after Christmas
- Likely that if the device removed – patient would die

Initial Thoughts

- General position is that an adult with capacity is entitled to refuse treatment
- Capacity?
- Would removal be getting too close to carrying out a positive act, the intention of which is to bring about the end of life – assisted suicide.
- Previous advice

Legal Position

- General position in law is that an adult with capacity is entitled to refuse treatment

- (B) adult: refusal of medical treatment all ER page 499

Request for information

- Why did patient wish to have the ICD removed?
- What benefit did he hope to gain from removal?
- Was the aim to end his life?
- Did he suffer from any psychiatric or psychological condition that might be contributing to his decision-making
- Was he capable of understanding the consequences of what he was asking for?
- Had he been fully consented to the removal of the device - post *Montgomery* consent issues – informed of material risks?

Family and Social Circumstances

- Family and social circumstances – possibility of undue influence
- Were family aware of the patient's request?
- Was there any welfare, guardian or attorney appointed?

Further Developments

- Telephone call 22nd December.
- Outcome of neuropsychiatry assessment and MRI scan awaited.
- Second psychiatric opinion from a colleague on capacity awaited.

Consultation with Counsel – March 2016

- Advice given
  - Any requests to have the device de-activated should be adhered to

Reason for that advice

- Confident regarding capacity
- Improvement in cardiac condition since September 2015
- Device could be de-activated and re-programmed without surgical intervention

De-activation of implantable cardioverter/defibrillators towards the end of life - A guide for Health Care professionals

- Ethical and legal aspects

If a person with capacity requests withdrawal of treatment, despite being fully informed of the likely consequences, healthcare professionals must comply with that request, even when they consider the request unwise or illogical or when the withdrawal of treatment is contrary to medical advice,. Should an individual healthcare professional be unwilling to take action where there is a properly established decision to deactivate an ICD, it will be necessary to identify another healthcare professional to carry out deactivation.

Some people may be concerned that ICD deactivation could be interpreted as a form of assisted dying, and as analogous to voluntary euthanasia or assisted suicide. That is not the case. Voluntary euthanasia and assisted suicide each involve an active intervention that in itself causes the person's death. The courts have confirmed that, when death follows withdrawal of treatment, the person's underlying condition is deemed the cause of death. Such withdrawal will be lawful, provided that it follows from the person's competent refusal of treatment or, alternatively, is in his or her best interests. In such situations, the healthcare professionals are released from any duty to provide treatment.

Cases are fact sensitive

- There may well be cases where it would be prudent to obtain prior approval from the Court – before acting - withdrawal or withholding artificial nutrition and hydration in relation to an adult in a minimally conscious state.

Guidance

Red = updates

RCP GUIDANCE UPDATED 2015
https://www.rcplondon.ac.uk/guidelines-policy/prolonged-disorders-consciousness-national-clinical-guidelines

SIGN GUIDELINE 2013 still in force – page 34
http://www.sign.ac.uk/pdf/sign130.pdf

BMA guidance issued 2016
https://www.bma.org.uk/advice/employment/ethics/mental-capacity/withdraw-withhold-artificial-nutrition-and-hydration

GMC guidance 2010 still in force:
http://www.gmc-uk.org/Treatment_and_care_towards_the_end_of_life___English_1015.pdf_48902105.pdf

but they now have an information page:
http://www.gmc-uk.org/guidance/28733.asp

Resuscitation Council 205 guidance still in force:
https://www.resus.org.uk/publications/cardiovascular-implanted-electronic-devices/

Where we are now..

- Device deactivated 22.3.16 following guidance from Central Legal Office, MDT meetings and patient involvement in process
- No further admissions with HF signs and symptoms or collapse
- Virtual review of patient via HFNLS
- Disappointed to ‘still be here’ but not suicidal
- Medications self discontinued Feb 2017
- Carelink home monitor unplugged March 2017
- Waiting

Lessons Learned

- MDT collaboration crucial
- Standard MDT now running fortnightly
- Patient with capacity has the right to choose
- Consent process – arrhythmia nurse service now addresses patient information and consent
- Consistency of colleague care – patients now referred to device clinics


Thank you

Questions for Panel Discussion