Mental Capacity, Personal Autonomy and the Nursing Home Resident

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Case Study - Mary T

Age 78 yrs NH resident
- Widowed - No Children - 3 sisters + 1 brother
Background

- Widowed early in marriage
- Worked in Cleary’s & minded ‘friend’s’ children for many years (vague + on details)
- Not outgoing socially
- Fragmented family contact for many years and did not like having her affairs discussed with them
- Family had been more actively involved in latter months but she was unhappy about that
- Aware she was in receipt of ‘widows pension’ but unclear as to how she managed bill paying
- Family concerns re her accusations about neighbours & family, losing items and money
- ?? Finances in ‘disarray’ until family were involved
Geriatrician review

• MMSE 22/30
• Personal Care good
• Clinical picture suggestive of Dementia with moderate cognitive impairment

• Vague on finances- signed cheques etc when same presented by family. No EPOA in place
• Aware she owned her own home
Recently

• Family approached DON concerned that ‘the friend’ who visits regularly is becoming involved with Mary Ts affairs

• ‘Notes’ (not in MT’s writing) found in her room with questions
  – Who selected the nursing home?
  – Who is paying for it?
  – Who is executor of my will?
  – What have I got in my will?
  – Did I sign anything for anybody about power of attorney?
  – Can I rent my house or sell it?

• The name and contact details of a solicitor - Not her own?
Highlights

• The family are at loggerheads - who’s responsible for administering her affairs?

• What position has ‘the good friend’? (Referred to in general discussion by MT frequently, nature of discussion suggests trusting relationship, ‘friend’ has not made herself known to NH staff)
‘Positive’ Risk??

• ? Who may have resident’s ‘best interest’ at heart
• Little objective evidence re what support from family or ‘friend’ prior to NH
• Can MT make decisions on her own behalf re her finances, friendships, family??
• What role for the NH staff in all this
Capacity

- Law - country specific
- Ethics
- Neuropsychology/ Psychometrics
- Practical
Approaches to Capacity

• **Outcome approach**
  – Capacity is determined by the content of the individual’s decision
  – Penalises individuality and demands conformity at the expense of personal autonomy.

• **Status approach**
  – One is capable either for all decisions or for none at all.
  – ‘Ward of Court’ and similar systems
  – Appropriate if severe dementia/coma only
  – Penalises those capable of making some decisions but not others

• **Functional approach**
Functional Approach

• Broad ethical, professional and, in many jurisdictions, legal consensus

• Incapacity defined by functional deficits judged to be sufficiently great that the person currently cannot meet the demands of a specific decision-making situation, viewed in light of its potential consequences (Grisso & Abblebaum 1998)

• Capacity depends on
  – Decision and context specific
  – Ability to make rather than nature of decision
  – Rational patients can make seemingly irrational choices: ‘Everyone has the right to be capricious, foolish, biased or prejudiced’. (BMA / Law Society)
### What decisions

**Table 1. Scope and Practice of Judicial Review of Various Civil Capacities in Older Clinical Populations**

<table>
<thead>
<tr>
<th>Civil Capacity</th>
<th>Scope of Abilities and Skills Required</th>
<th>De Facto Practice of Judicial Review</th>
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</thead>
<tbody>
<tr>
<td>1. Independent living</td>
<td>Broad; involves cognitive and procedural skills</td>
<td>Yes; when another party petitions for guardianship, or if elder abuse discovered</td>
</tr>
<tr>
<td>2. Financial management</td>
<td>Broad; involves cognitive and procedural skills</td>
<td>Yes; when another party petitions for conservatorship, or if elder exploitation discovered</td>
</tr>
<tr>
<td>3. Treatment consent</td>
<td>Narrow; primarily a cognitive task</td>
<td>Rarely; only in contested situations with conflict between family or health care professionals</td>
</tr>
<tr>
<td>4. Testamentary capacity</td>
<td>Narrow; primarily a cognitive task</td>
<td>Rarely; only in contested situations (often postmortem)</td>
</tr>
<tr>
<td>5. Research consent</td>
<td>Narrow; primarily a cognitive task</td>
<td>Very rarely; only if brought for litigation</td>
</tr>
<tr>
<td>6. Sexual consent</td>
<td>Narrow; primarily a cognitive task</td>
<td>Very rarely; only if brought for litigation</td>
</tr>
<tr>
<td>7. Voting</td>
<td>Narrow; primarily a cognitive task</td>
<td>Extremely rarely; in most states voting rights remain even under plenary guardianship</td>
</tr>
<tr>
<td>8. Driving</td>
<td>Moderate; primarily a procedural task</td>
<td>Rarely; only if arises in context of guardianship, although registries of motor vehicles may suspend license without judicial review</td>
</tr>
</tbody>
</table>
Distinction “between competence generally, on the one hand, and the lack of capacity to make a particular decision”

Judgement, that the Jehovah’s Witness patient while generally competent, lacked capacity to refuse a blood transfusion, was based on a functional approach to capacity.
‘Capacity means the ability to understand the nature and consequences of a decision in the context of available choices at the time the decision is to be made’.

• Implications:
  – Allows autonomous individuals to make their own choices
  – These patients should be supported to facilitate making their own choices
  – Take past wishes into account
Principles

• **Presumption of capacity** unless the contrary is established
  – Not incapable merely by reference to age, appearance, condition, behaviour or nature of decision
  – Cognitive deficits only matter if relevant to decision at hand

• **Duty to maximize capacity**
  – Treat delirium, depression, sensory disabilities; choose best location and time for assessment
  – Education even if there has been extensive prior discussion.

• **Account must be taken of a person's past and present wishes, where ascertainable’**

• **Decisions should be the least restrictive** of the person's rights and freedom of action and in his or her best interests
Lacking Capacity to Make Decisions

• Unable to:

  – understand the information relevant to the decision
  
  – retain that information
  
  – use or weigh that information as part of the process of making the decision or
  
  – communicate decision by any means
Autonomy and Capacity

• Competent patient’s wishes are paramount

• Incompetent patient
  – Advance directive
  – Patient designated surrogate
  – Legally designated surrogate
  – ‘Best interests’
‘People who lack capacity to make a decision will nevertheless be able to express a preference to receive or forgo an intervention. Even in the presence of incapacity, the expressed view of the patient carries great weight and, except in emergencies, it may often be impractical or undesirable to try to impose care, treatment or investigation on someone who refuses it. Legal advice should be sought in respect of refusal of any major intervention including surgery, prolonged detention or other restrictions on liberty’.
The views of those who have a close, on-going, personal relationship with the person such as family or friends are often helpful in the discussion and decision-making process for those who lack capacity particularly with regard to providing greater insight into the person’s previously expressed views and preferences.

*However, no other person such as a family member, friend or carer (and no organisation) can give or refuse consent on behalf of an adult who lacks capacity to consent unless they have specific legal authority to do so*. 
Using Mental Status Tests to Determine Capacity?

• NO! - directly counter to functional decision-specific approach!

• How can a score determine ability to handle a specific question?

• Questions such as orientation, pentagon drawing identity of President have no direct bearing on the matter at hand

• Risk of reversing presumption of capacity based on an arbitrary score (‘But his MMSE is only 14’!)
Problems

• Agreement between expert clinicians when making capacity assessments is relatively poor.

• What threshold, or standard, for capacity
  – ? Higher for more serious decisions (sliding scale approach)
  – Potential for finding a substantial proportion of hospital patients being judged incapable of making their own decisions

• Emphasis on rational decision making does not reflect modern views on how people actually make decisions.

• Decision-specific approach to capacity raises the spectre of multiple separate capacity judgements each day for patients with complex illnesses
How people really make decisions

- Limited information processing capacity or skill
- Difficulties with numbers
- Perceptual biases
- Social pressures and norms
- Use of heuristics (short-cuts)

(Kahneman & Tversky, 1984)

- Screen out important information
- View the problem in terms of familiar issues or problems
- ‘It’ll never happen to me’ (Smokers worry more about the dangers of food additives than those of tobacco - Lave, Science 1987)
Some solutions?

• Ensuring appropriate “triggers” for capacity assessment

• Acknowledging medical uncertainty

• Allowing delegation of decision making

• Setting an attainable threshold for capacity

• Only intervene if alternative decision-maker can do better
The 6 Step Capacity Assessment Process (Darzins, Molloy & Strang, 2000)

**Step 1:** Ensure valid trigger is present

**Step 2:** Engage person in the capacity assessment process

**Step 3:** Gather information about issues, available choices and consequences of choices

**Step 4:** Educate about the issues, choices and reasonably foreseeable consequences of choices

**Step 5:** Assess capacity with respect to the specific issues

**Step 6:** Act on the outcome of the assessment

**Pre-assessment tasks**

**Post assessment tasks**
In Practice?

• Competence judgments are value laden, frequently subjective and inconsistent (Brindle & Holmes Age Ageing 2005)

• Trigger for assessment is usually disagreement with recommended treatment or societal unacceptability

• High threshold for capacity when perception of ‘at risk’: falls (restrain), wandering (lock up), ‘what ifs’ etc

• ‘Gotcha’

• Can patient really understand, appreciate the consequences of, reason.....
De facto imprisonment in nursing homes

• A cross-sectional prevalence study amongst residents in randomly selected non-specialist nursing homes in South East England.

• 445 residents randomly selected from 157 nursing homes.

• 14% (64) of the residents interviewed lacked the capacity to consent to residence.

• 6.1% (27) of residents were prevented from leaving but less than half of these lacked the mental capacity to consent to residence.

(McDonald et al, Aging Clin Exp Res. 2004)
Best Interests – Standard Argument?

• You are not able to care for yourself properly

• You will be better off in residential home where you will receive such care
How better off?

• It’ll be nice for you to be with other confused people?
• You’ll be less confused?
• You’ll be happier?
  – ‘Increased feelings of loneliness and marginalization; psychiatric symptoms worsened and quality of life perceived more poorly’. (Scocco, Int J Geriatr Psych 2006)
• You’ll get better medical care?
  – Antipsychotic medication misuse
  – Restraints
  – Poorer management of chronic diseases
• You’ll live longer?
  – Shorter life expectancy in Alzheimer’s disease admitted to LTC (McKee, J Gerontol 2006)
Conclusions

Need for broader view of capacity
Maintain presumption of capacity with focus on triggers
Bias in favour of competence / autonomy if doubt
‘Welfare’ not the same as safety or medical well being
Threshold should be low, eg consistent, coherent wish with some idea of (real rather than ‘what if’) risks
Case Study - Mary T

Revisited
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Will Making by Older People in Residential and Day Services
HSE Guidelines

<table>
<thead>
<tr>
<th>Document reference number</th>
<th>NEASC03</th>
<th>Document drafted by</th>
<th>National Elder Abuse Steering Committee</th>
</tr>
</thead>
<tbody>
<tr>
<td>Revision number</td>
<td></td>
<td>Document approved by</td>
<td>ISD Management Team</td>
</tr>
<tr>
<td>Approval date</td>
<td>17 Jan 2012</td>
<td>Responsibility</td>
<td>National Director,</td>
</tr>
</tbody>
</table>
• Staff ....must therefore be alert to the possibility that in certain circumstances some older people may be vulnerable to financial abuse.
• Financial Abuse can also be defined in relation to behaviour such as; forced to give money or property, denied access to money or property, stolen money or possessions, forced/misled to sign over ownership of home or property....forced to change a Will. (‘Abuse and Neglect of Older People in Ireland’, Report on the National Study of Elder Abuse and Neglect, NCPOP 2010.)
• An older person has a fundamental constitutional and human right to privacy and to consult their solicitor without the requirement to inform the unit of their doing so.
• A solicitor visiting an older person in a professional capacity does not necessarily have to inform the unit of their visit as circumstances may arise where the older person does not wish the unit to know that they have a solicitor visiting.
If a solicitor .. [visits] .. an older person and there are concerns about the older person’s capacity.
• Inform the solicitor of the concerns and the fact that the unit will be recording those concerns on the older person’s file.
• Any concerns as to capacity and vulnerability should be recorded on the older person’s file and line manager should be informed.
• Records re a solicitor’s visit should be clear and comprehensive.
• Older people should be told not to sign any document without fully understanding its contents and effect [and] should be supported and encouraged to obtain independent legal advice.
• The line manager may consult with the Senior Case Worker for the Protection of Older People regarding the concerns.
• Any concerns of financial abuse should be reported to HIQA within 3 working days.
Family members who raise queries with regard to an older relative’s affairs should be directed to their own solicitor.