PDQ: giving a second opinion

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Content

• All based on
  ➢ BMA/RCP (and new PDOC) guideline
  ➢ my experience since July 2018

• Covers
  ➢ Overall goals of process
    • And goals of the visit
  ➢ Process from contact to conclusion
  ➢ Data on experience
Messages

• Very poor understanding of & adherence to Mental Capacity Act 2005
  ➢ Across all organisations and teams
  ➢ Extending well outside patients in PDOC

• Second opinions require hard work:
  ➢ Getting evidence, thinking etc
  ➢ Time involved considerable
    • Up to 24 hours, often 12-17 hours
Second opinion: the goal is to:

- Provide a comprehensive report to show that decisions made are sound:
  - Reviews all the relevant evidence
    - Not simply repeating information given
  - Discusses all the major issues
    - Especially any raised by clinical team and/or family members
  - Explains clearly, and justifies, the final conclusion(s)
  - Sets out any recommendations clearly
The start

• Initial contact is often
  ➢ by someone not directly involved
    • Solicitor, CCG, secretary, junior doctor
  ➢ by phone or short email
    • Rarely any clinical or other information
  ➢ made after many delays
  ➢ Requested to resolve a difficult situation
    • Not simply restricted to CANH decision

• BMA/RCP guidance rarely followed

https://www.bma.org.uk/advice/employment/ethics/mental-capacity/clinically-assisted-nutrition-and-hydration/decision-making-process
Therefore need to:

• Establish the context of the request:
  - History and current issues
  - Any disputes, differences of opinion
  - Expectations of:
    - Patient, family, advocates
    - Clinical team and organisations involved
  - Who is clinically requesting the opinion
  - Who is commissioning the report
Practically one needs to:

- Establish the **primary contact person**, who must take **full personal responsibility** for:
  - Obtaining **all** required information
  - Ensuring everyone knows about the second opinion
  - Arranging any meeting(s) needed
  - Notifying relatives and ensuring some will be present (& IMCA if involved)
It is wise to

• Write to confirm and clarify
  ➢ Responsibilities of primary contact
  ➢ Likely time-scale, time involved, dates
    • Or date and time if agreed
  ➢ Your needs
    • information, room, access to notes, etc
  ➢ Contractual status
    • Money, liability etc
Referral documents

• Rarely get any documentation before visit
  ➢ Request it, but unlikely to arrive
    • Disorganization, low priority, etc

• Should not rely solely on information given, however good
  ➢ If checking, must review original data
    • Risk making same mistakes as referring person
    • i.e. decision may be sound on information given, but information may be incomplete, mistaken etc
Stress need copies of/access to:

- **All** notes from acute, early months
  - And all later discharge summaries/letters
- **All** brain imaging study reports
- **All** formal assessments, summaries etc
- **All** minutes of any best interests meetings
- A dedicated, private space
  - to interview staff and relatives
    - staff must be allowed time if needed
Before visit:

• Confirm visit with the place the patient is in, 1-2 days beforehand
  ➢ Has person died?
  ➢ Are staff and relatives aware of your visit?

• Review any information provided
  ➢ Digital copies of notes
  ➢ Emails, letters etc
Visit – goals are to:

• Ensure that family/friends
  ➢ Have been listened to carefully
  ➢ Have been given correct information
  ➢ Have had answers to all their questions, doubts and concerns
  ➢ Fully understand the situation and process
Visit – goals are to:

• Confirm correct neurological assessment
  ➢ Nature, extent, location of damage
    • Presence of additional factors or diagnoses
  ➢ No other contributing factors missed

• Confirm correct prognosis has been given
  ➢ And in terms of best likely
    • Social interaction
    • Functional autonomy
    • Residential setting
    • Experience of pain/pleasure
Visit – goals are to:

• Confirm patient’s factors determining best interests correctly identified
  ➢ Past/present wishes, feelings, values, beliefs, and ‘other factors’
  ➢ From family (try to see some)
    • Were any people excluded (Bias)

• Confirm best interests decision based on:
  ➢ Correct process
  ➢ Correct facts
  ➢ Logical, justifiable use of facts
Visit – goals are to:

• Ensure proper planning for end-of-life, if that is the outcome:
  ➢ Involvement of palliative care
  ➢ Where it will occur
  ➢ Correct estimate of duration given
  ➢ Any specific issues

• **Note:** this is *not* essential before visit
  ➢ Should make recommendations
Note that:

• Assessment of level of awareness is **not** a central issue.

• Need to confirm:
  - Lack of mental capacity
  - Current level of experience of pain/pleasure
  - Current level of social interaction, functional autonomy, care needed

• The main issue concerns **acting in the best interests of the patient**
Proforma/guidance

• Gives the main domains to be covered
  ➢ When referring or giving a second opinion

• But often not suitable because:
  ➢ Case has additional complexity (v common)
  ➢ Case not covered
    • Not PDOC, v early, v late, can/could feed
  ➢ May inhibit or constrain information
    • May leave areas not discussed

• Always a check-list; useful in some cases
Note that from my experience:

• I do **not** use the proforma provided:
  ➢ It does not/cannot allow cover particular issues concerning clinicians, CCG, family
  ➢ It focuses unduly on less relevant factors
    • Level of awareness, and
    • Past rehabilitation
  ➢ The primary issues are
    • Patient’s experiences, autonomy, wishes etc
    • Prognosis, including potential interventions
Experience

• Since July 2018, I have undertaken 20 second opinion assessments
  ➢ All in England and Wales
    • 11 in nursing homes, 8 in hospital, 1 at home
    • 16 funded by NHS, 2 by family, 2 by nursing home
  ➢ Two not directly about CANH
    • Disputed best interests and major decision
  ➢ Not all really PDOC (half ‘emerged’)
    • overall 3 ‘conscious’ people over 2 yrs
Experience - failures

- Striking
  - unawareness of the process and
    - Failure to use or look for guidance available
  - Failure, and usually unwillingness to
    - Initiate and undertake any best interests process
    - Discuss potential treatment withdrawal
  - Failure to give families accurate information
    - Clinical, and
    - Concerning best interests process
Experience - difficulties

• Difficulties in
  ➢ Getting funding agreement for opinion
    • Refused by CCG in one case despite guidance
  ➢ Obtaining copies of notes, reports, summaries
    • Often hospitals refuse/delay
  ➢ Organising best interests meeting, when needed
Experience - clinical

• Age ranged from 17 to 85
  • Median 50, IQR 47-58

• Causes:
  ➢ 10 cerebral hypoxia
  ➢ 4 subarachnoid or intracerebral haemorrhage
  ➢ 2 stroke/cerebro-vascular disease (1 also TBI)
  ➢ 3 traumatic brain injury
  ➢ 1 hyperglycaemia
Experience – time data

• Delay from onset to best interests
  ➢ 14 days – 8 yrs; median 344 days
  ➢ BI to request; - 13 days to 338 days
    • Two cases I did the best interests meeting
  ➢ Request – assess; 1 to 162 days
  ➢ Assess – report; 0 – 4 days

• Time taken (hours & minutes)
  ➢ 10h 20m – 23h 15m, Median 13h 23m
Conclusions

• Giving a second opinion is:
  ➢ Very interesting, but a great challenge
  • Organisationally, obtaining evidence. Personally
  ➢ Time consuming

• The process of managing patients is poor
  ➢ Some notable, rare exceptions
  ➢ May have to do the process for the referrer

• Second opinions vital outside PDOC

• Guidelines not used; but should be
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