PDOC: 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 a**re
    - 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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