

SCIE case study: Importance of mental capacity advocacy: Ms. C

Background: The patient, Ms C, is a mature woman with severe physical and learning disabilities who has spent her whole life in institutional care. Following the closure of the hospital where she lived for many years, she moved to a small specialist group home. She has only one living relative; this relative is not in touch with her or engaged with her care.

She is non-verbal, does not sign and has no understanding of language. She communicates very little, even non-verbally. Staff who know her believe that they are able to identify her mood from her behaviour. She is dependent on staff for all aspects of her daily living.

She suffers contractures of her limbs and is conveyed in a specially adapted wheelchair. She has no independent mobility and has to be lifted by staff.

She engages in some repetitive behaviours (banging her face and one side of her head) which have resulted in injury. She wears a helmet to prevent her from harming herself.

It was noted two years ago that she had severe cataracts, which render her largely blind. No history for the development of these cataracts was obtainable, so they may have been present for many years or decades. It was suggested that these might be treated through cataract surgery.

She was initially assessed by a consultant surgeon and nurse at Whipps Cross Hospital. Although the team was in principle willing to undertake the surgery and make necessary adjustments (e.g., allocating a longer time and additional staff to manage her; making provision for her severe physical disabilities during the surgery) they concluded that the surgery would not be in her best interests due to:

- Her head banging, which could dislodge the implanted lens and result in damage which would outweigh any benefits of surgery
- The impossibility of assessing her sight, due to her lack of communication
- The combative non-co-operation with clinical treatment which was evident on the day of her assessment
- The absence of evidence that she was aware of her sight defects or that she would gain any detectable benefit from surgery to improve her sight.

This decision prompted concern in the light of possible non-compliance with the Mental Capacity Act.

What did not work well:

Lack of awareness of the detail of the Mental Capacity Act and Equalities Act: The staff who assessed Ms C were working in accordance with the spirit of both Acts, in the sense that they had clearly assessed her as lacking in capacity to take this decision, were committed to making a decision in her best interests and were ready to make reasonable adjustments in order to support surgery in the event that this could be undertaken in her best interests. However, they were unfamiliar with the detail of the Acts and had little experience of making adjustments to meet the needs of a person with Ms C's level of need.

Lack of consultation: Ms C had no involved relatives, and the clinical team were not aware of the obligation to involve an IMCA in this situation. No consultation therefore took place. No formal best interests meeting was held prior to taking the decision not to treat.

Lack of history: The hospital where Ms C had lived most of her life had closed and her current carers have no detailed clinical history for her. No information was therefore available as to the duration of her cataracts or about how they had affected her. Her profound learning disabilities made it impossible to assess whether she was conscious of her poor or worsening vision.

Lack of advocacy by the care home: Ms C was escorted to her appointment by a rather disengaged and apparently junior staff member from her residential home. This staff member was not able to provide any useful information about the patient, beyond what was available in the referral letter, and clearly had no expectation of advocating on Ms C's behalf or becoming involved in the decision making process. Very little information about the patient or her history or her daily life was therefore available to the clinical team at the point when they made their decision. They therefore did not know, for example, that Ms C's head banging only affected one side of her face, since her other hand is largely paralysed.

Delays in addressing concerns: Although concerns were raised soon after the decision not to proceed with treatment, it was several months before these concerns were addressed through a meeting with the clinical team. This reflected the team's strong view that surgery was impossible.

What worked well: The key factor in resolving this case was the lengthy best interests meeting which was eventually held. This meeting involved the Consultant Ophthalmologist, a senior nurse from the team, the Trust MCA lead, and the patient's IMCA.

The involvement of the IMCA: Prior to the meeting, the IMCA had explored the patient's needs and abilities more fully and more skilfully than the ophthalmic team had been in a position to do. This included meeting with the patient herself and talking in detail with staff at the care home who were able to tell him more about her life and behaviours. As a result, he was able to bring information which had not been apparent at the initial meeting, including information which suggested that her combative behaviour at her first assessment was atypical for her.

The IMCA also played a key role in challenging the consultant's belief that the surgery could have no benefit for the patient. The consultant was aware of cases where patients with psychological difficulties had responded very badly to improved sight (a risk which has still not been resolved). The consultant also felt that in the face of Ms C's complete dependency, increased sight could confer no practical advantages, and that in the face of her profound deficits, it could convey little subjective benefit – e.g. she did not have a level of understanding which would allow her to interact with the world or to understand television, let alone to read. The IMCA, however, argued strongly that, in the absence of any evidence to the contrary, it must be assumed that it would be in the patient's interests to have improved sight, as an absolute benefit. He also brought some information which suggested, circumstantially, that she might like this. For example, staff had reported that she appeared to enjoy stimulation in other modalities, e.g. smell, sound, and taste.

A further important contribution of the IMCA was the simple tenacity of insisting that the case be reviewed, which would not otherwise have happened.

MCA awareness: Prior to the meeting, the MCA lead discussed the case with the Consultant, and went through the relevant legal requirements, which clarified many points which had not previously been understood.

Engagement of consultant and nurse: Having raised awareness as above, and discussed the case in considerable detail at the meeting, the Consultant and Nurse were active and engaged in thinking

creatively about possible adjustments that could be made in order to overcome the barriers which had previously seemed insurmountable, e.g.:

- Agreeing that a standard lens could be used to provide some improvement to sight, even though it was impossible to use normal measurements of vision
- Suggesting that only one eye be treated, i.e. the one which the patient could not easily reach and therefore would be less likely to damage following surgery
- Arranging a trial of eye drops, to try to acclimatise the patient to the aftercare which would be required
- Making contingency plans for alternative treatment that could be given by injection if the patient refused eye drops

What could be done differently?

Training: The case clearly highlighted the need for additional training in relation to the Mental Capacity Act, which has been arranged. Although training had been provided to Consultant Ophthalmologists a few months previously, this had not covered the issue of “adjustments” and had only lightly touched on the need to involve IMCAs. These issues are now highlighted in Consultant training relating to the mental capacity act.

Communication with the home

If the patient had been accompanied by a more engaged member of the team, much more information about the patient would have been available and might have led to a different assessment of the patient’s needs. The need for the patient to be accompanied to appointments by a person who is in a position to engage with decision making will in future be stressed when a patient with known learning disabilities is assessed by the team.

Involvement an IMCA

The team is now aware of the legal requirement to involve an IMCA when a patient without capacity has no one else who can be consulted. The benefits of this involvement were very apparent in this case, which has effectively underlined the message here – to the extent that the team were disappointed that an IMCA could only be involved in the absence of any other consultee. It was agreed that in future, where it became apparent that a patient did not have capacity, the decision on treatment would be deferred, to allow the necessary consultation and best interests meeting to take place, involving the team, relatives/carer/advocate.

What is the learning – good and poor practice?

- Legal requirements: be aware of the legal requirements in their detail, and consult Trust or other experts in any situation where the legal requirements are unclear.
- Approach the issue of “best interests” with the assumption that the patient has the same basic needs as anyone else, however, profound their disability.
- Be really well informed about the patient – by whatever means and from any reasonable informant – before making decisions about them.
- Be creative in thinking about reasonable adjustments

Concluding comments

Ms C has not yet had her surgery. Arrangements have been made for her to be assessed anaesthetically, and it may be felt, in view of her multiple physical co-morbidities, that the necessary

anaesthesia could not be safely achieved. If the surgery goes ahead, it will not be possible to tell until after the surgery – if at all - whether it will benefit her. It remains possible that – as feared by the consultant – increased vision may distress more than benefit her, or that her behaviours in response to surgery may actually result in further damage to her sight. It is also possible, on the other hand, that it will give her a significantly enriched, more pleasurable and more meaningful life, allowing her more understanding and orientation than she currently has. Given her lack of communication, we may never know whether she is even aware that her visual field has changed.

In this sense, the jury is therefore “still out” as to whether the team has now made the right decision in this case. Nonetheless, as a result of this case, the team is much more aware of the breadth of issues involved in making decisions on behalf of patients with severe learning disabilities, of the range of provisions available to protect these patients, and of the positive role that they as clinicians can play in seeking the best possible outcome in these difficult cases