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The Challenges of Amnesia in Assessing Capacity, Assigning a Proxy, and Deciding to Forego Life-Prolonging Medical Treatment

Catherine Myser

Catherine Myser, PhD, is the Founder of Bioethics By and For the People, Cross-Cultural & International Partnerships for Democratic Bioethics in Berkeley, California, catmyser@hotmail.com. ©2007 by *The Journal of Clinical Ethics*. All rights reserved.

We make and remake ourselves through memory; we move through time like whales, filtering experience from our surroundings, digesting, repackaging, deciding what to keep and what to throw away. We assemble ourselves, piece by piece, from recollections. We are what we remember.

Memory, individual or collective, not only makes us what we are, but in a sense gives us the power to travel through time, projecting ourselves into the future. Our stories — at least some of them — will outlive us. And it’s not hard to imagine a scenario in which our stories — our memories — become overwhelmingly important . . . [for example] in [apocalyptic science fiction] a handful of hardy survivors is spared, to be collectively confronted with the overwhelming task of . . . building the future and rebuilding the past. . . . From your rich accumulation of memories, you would shape the future, passing on a lifetime’s supply of internalized input to your children and grandchildren, and all the other struggling members of your . . . tribe.

— Rebecca Rupp, *Committed to Memory: How We Remember and Why We Forget*

SPECIAL CHALLENGES OF MR. G’S AMNESIA IN ASSESSING CAPACITY

The 58-year-old Mr. G has “lost virtually all of his recent past.” The etiology of his amnesia is unclear, but existing speculation is that it was due either to a recent truck accident resulting in seizures (or vice versa) and subsequent mental status changes, or to possible brain metastases (presumably affecting brain structures associated with memory). In any case, further neurological and oncological work-ups relative to Mr. G’s amnesia have not been pursued. Despite this lack of relevant data, earlier neurology chart notes suggest that Mr. G has a “poor prognosis for regaining memory.” All the same, Mr. G faces a series of complex medical and ethical decisions due to his unexpected diagnosis of “aggressive lung cancer. . . . very aggressive tumor”

discovered during the same admission. This cancer "can be treated early on with a 15 percent curative rate and a 60 percent rate of response that would extend the patient's life, but likely only for about one year," but requires a chemotherapy regime that is "rigorous" and "very burdensome with expected side-effects" of nausea, vomiting, fatigue, and hair loss.

The first challenge in Mr. G's case study is thus to assess his capacity — carefully considering his amnesia diagnosis and prognosis — to distinguish if consent should be sought from Mr. G himself, or from a proxy decision maker (and if so, how he/she should be chosen), relative to whether possible life-sustaining chemotherapy treatments should be accepted or refused, including whether to pursue further diagnostic and prognostic information that might inform that choice. As the assessment of capacity is the legitimate "gatekeeper"¹ to latter components of the informed-consent process — disclosing information, ensuring understanding² and voluntariness, obtaining consent — I would argue that Mr. G's amnesia should first and foremost be as rigorously and comprehensively evaluated as possible, to determine his specific capacity relative to each task or decision systematically to be considered, and in order of priority.

In this context, it seems as if more extensive testing by the neurology service and/or a cognitive scientist or an expert on memory disorders (as possible, given Mr. G's current condition, but there is clinical precedent that it is possible) would offer very useful information. Another important consideration — also weighing Mr. G's diagnosis of amnesia and his prognosis — would be whether his capacity could be restored, even if it is judged at present to be inadequate to one or more of his current decision-making tasks. If so, it remains our ethical obligation to restore his capacity as possible, and only then take up making decisions about assigning a proxy and/or accepting or refusing further diagnostic information and treatment (although the urgency of this particular cancer diagnosis obviously limits that opportunity for the present). Also, there seems to have been little discussion of whether there would be additional useful strategies (beyond posting signs to help Mr. G locate his door and bed, and family photos posted in his room) to help manage Mr. G's amnesia, or to tap into any remaining long-term memory, and/or rehabilitate any specific current deficits in his memory function as possible. Curiously, it seems as though the diagnosis of cancer in this case, and the concurrent acceptance that the proxy decision maker was "adamant that [Mr. G] would not want any further work-up or treatment," may have superseded more precise neurological and amnesia and memory evaluation and capacity assessment, which unfortunately placed the (oncology) cart before the (neurology/amnesia/capacity) horse.

Although we cannot now secure this important data, I believe it is the lack of this core information that leaves Mr. G's daughters and healthcare team confused about his capacity to make various decisions, and causes considerable "lingering questions" and concerns — about Mr. G's capacity, his appointment of a proxy, and his proxy's decisions, at possible great cost to Mr. G — throughout the case study as told. In an actual case consult, we would begin by assiduously getting any and all such relevant facts about Mr. G's complex neurological and oncological conditions absolutely clear. As that is not possible in a case study that has been appropriately masked to protect the confidentiality of the patient and family, I ask the reader's indulgence to attempt at least some additional specificity, as a legitimate ethical analysis of the case would necessarily hinge on Mr. G's complex neurological status. I will therefore try to show how such data might clarify the series of decisions affecting Mr. G by hypothesizing as to his specific amnesia diagnosis. (Needless to say, this kind of hypothesizing is never appropriate in an actual clinical ethics consult, and certainly not by an ethicist who lacks relevant clinical expertise, including myself, and even physician-ethicists in specialties outside the particular clinical diagnosis and prognosis sought).

In an actual clinical consult, one would look to the relevant clinical experts for diagnostic and prognostic information on Mr. G's amnesia. In lieu of this — for the purposes of this case study only — the following brief review of some relevant literature will have to suffice as a substitute for the input that would normally and appropriately be sought from the relevant clinical experts. So I do not mean to establish any dangerous precedent (do not try this at home!). Rather, in a case study alone, this might be a useful hypothetical exercise, to illustrate a crucial gap in information, and why and how one could better proceed in making decisions while in possession of such core clinical information. I aspire only to specify Mr. G's "short-term

memory loss" and "severe memory loss" further as possible, to adequately address challenges, including:

- Assessing such a patient's capacity,
- Securing such a patient's informed consent (directly or via proxy), and
- Interpreting such a patient's (or proxy's) acceptance or refusal of possible life-prolonging diagnosis and treatment.

A BRIEF LITERATURE REVIEW TO EXPLORE THE DIAGNOSIS OF AMNESIA

Different amnesic syndromes have very different characteristics, and it is thus valuable to focus on the most likely amnesic syndrome given Otto's description. Otto's analogy to the film *Memento* — in which the main character has a specific diagnosis of anterograde amnesia (AA) — in her title and in the body of her case study is telling.³ Otto's shorthand description of Mr. G having "short-term memory loss" is more ambiguous, but one memory disorder expert acknowledges, yet also dismisses, such short-hand language also common in the context of AA, clarifying that in "anterograde amnesia . . . it's not that [one] loses memories, it's that [one] can't form them in the first place."⁴ In other words, the main problem for a patient suffering AA is converting the "will-o-the-wisps" of new, time-limited "short-term memory" or "working memory" (the latter sometimes also referred to as "scratchpad memory" or "the blackboard of the mind") into "the solidities of long-term storage," a process called "consolidation."⁵ Echoing these descriptions, the wife of well-known AA patient Clive Wearing characterizes his AA (with additional retrograde amnesia) thusly: "Every conscious moment is like waking up for the first time. New information 'melts like snow, not leaving a trace'."⁶

Despite losing the ability to retain new information, patients with AA (sometimes referred to as "pure memory disorder") retain intact immediate recall of new information within the scope of short-term memory or working memory. In addition, they retain the intact ability to retrieve information that was consolidated and stored before the onset of the memory disorder (remote recall), although this can be decreased somewhat if they also develop a measure of retrograde amnesia, thus losing a portion of their stored memories as well. They also retain other cognitive abilities, such as language and visual spatial processing, and their intelligence is usually normal. Certain implicit and procedural memories also remain substantially intact.⁷ Residual learning capacities can include the following:

- Motor learning,
- Skill learning (with an absence, however, of explicit memory or declarative memory, so the patient will not remember the learning sessions or the details thereof),
- Repetition priming (for example, when an individual encounters stimuli on a study list — for example, words with similar word stems — it may influence the individual's successful performance on a subsequent test, for example, completing primed word stems with primed versus unprimed words),
- Personal semantic memory, favored by being learned slowly over an extended period of time (for example, an individual may be able to construct a cognitive map of the layout of a new house, moved into after the onset of the memory disorder, as the result of thousands of learning trials of daily locomotion from room to room, thereby encoding the location of each room relative to other rooms; this raises the possibility that an AA patient also might be able to acquire new vocabulary words if daily training is carried out over a period of years).⁸

More intriguingly for our purposes, brain and cognitive sciences researcher Suzanne Corkin of MIT argues that H.M., the most renowned AA (and retrograde amnesia) patient (studied by some 100 investigators over 54 years),

has beliefs, desires and values that are always present, [for example] he believes that doing crossword puzzles helps him to remember words and is fun. He is altruistic. . . . His social behavior is appropriate and courteous. . . . He has high moral standards with respect to right and wrong in his personal conduct. . . . He has a conscience. . . . In addition, he has good insight into his memory disorder . . . a sense of

humour, and often makes jokes. . . . [However] his ability to interpret and report internal states is diminished. Specifically he has an impaired ability to identify and respond to painful stimuli, and shows no difference in his ratings of hunger and thirst made before and after a meal.

Also, in the first five years of H.M.'s AA, "an extensive test battery failed to reveal any deficits in perception, abstract thinking, or reasoning ability."⁹ Perhaps on the basis of these and other retained abilities, despite the deficits also described, an AA patient can seem relatively normal, at least in the moment. Rebecca Rupp reminds us, however, that "H.M. forgets all that has gone before. Enter a conversation with H.M., leave the room briefly, and upon your return, he will have forgotten who you are. Life has no continuity for H.M., the thread of his being was chopped off short [54] years ago. 'Every moment,' he once told a team of interviewing doctors, 'is like a waking dream'."¹⁰

Armed with the above brief specifications of AA in mind — but with no pretense of possessing either neuroscience or amnesia expertise or the actual facts of Mr. G's case — we can now consider the key ethical questions in Mr. G's case study in a somewhat more targeted fashion. This is important if for no other reason than to highlight how crucial getting this information would be for addressing any and all ethical issues in this case. Pointing out both this critical gap in data, and the need in any actual consult to seek further such diagnostic and prognostic information from the relevant clinical experts (first and foremost to assess patient capacity), would be a legitimate contribution from a consulting ethicist concerned with the ethical issues in this case study.

RELEVANCE OF MR. G'S AMNESIA IN ASSIGNING A HEALTH PROXY

If Mr G's care team had been able to obtain detailed information regarding his amnesia from the neurology team, and/or if experts in cognitive science or memory disorders had been able to thoroughly evaluate his amnesia, it might have been possible to sort out these capacity questions relative to Mr. G's assigning a proxy as follows.

1. If Mr. G's appointment of his brother as proxy was the result of past discussions and decisions to have his brother serve as his proxy for any medical decisions for which Mr. G himself would, in the future, lack capacity, and
2. Mr. G could retrieve this information from his long-term memory,
3. There would be no reason to suspect that Mr. G did not possess the ability that would be directly relevant to the task of selecting and appointing a proxy decision maker.

According to the descriptions of AA above, Mr. G's access to such long-term memories could be retained, despite Mr. G's other described memory deficits in consolidating future long-term memories. We are given no evidence to suspect that Mr. G. does not retain this ability, or access to his long-term memories, in which such discussions and decisions might generally have been stored. Thus Mr. G's clear recognition of his brother (and other family members from photos and in person), and repeated confirmations that his brother should serve as proxy — to interpret Mr. G's own longstanding values and beliefs about "quality of life" and the "benefits and burdens" of particular treatments, and apply these values and beliefs as best a proxy can to Mr. G's current medical condition and decision making — would not be problematic. The "consistency" of Mr. G's preferences in this regard might thus be accepted as a legitimate designation and confirmation of his proxy decision maker.

It would not be appropriate to accept Mr. G's brother as a proxy because it seemed "comfortable" or "logical" to the healthcare team, nor because the appointment of a proxy is a "less-sophisticated decision." In fact, proxy appointments are often plagued with considerable challenges and complexities. Rather, this proxy appointment would be acceptable because Mr. G would be judged on the basis of careful and comprehensive evaluation of his particular amnesic syndrome, to retain the abilities most relevant to appointing a proxy.

On the other hand, if the healthcare team or members of Mr. G's family suspect — or can clearly demonstrate — that no such past discussions or decisions regarding a proxy ever took place, and instead are able to determine that this proxy appointment, "made on [Mr. G's] admission," was somehow coerced and/or subjects Mr. G to coercion or manipulation and/or involves some ethically problematic aspect of the family's history of estrangement and mistrust (although these would have to be rigorously defined and demonstrated, and not rely on mere rumor or speculation), the healthcare team and/or family might have legitimate concerns.

Sadly, in the absence of an adequate evaluation or diagnosis regarding of Mr. G's amnesia, his daughters and care team cannot be reasonably certain about his abilities, and, as a result, are confused when Mr. G appears to be "lucid in the moment," but unable³³ to assimilate (consolidate) his cancer diagnosis or remember new care team members and crucial treatment discussions from hour to hour and day to day.

THE RELEVANCE OF MR. G'S AMNESIA IN DECISIONS TO FOREGO POSSIBLE LIFE-PROLONGING TREATMENT

If Mr G's care team had been able to obtain detailed information regarding his amnesia from the neurology team, and/or if experts in cognitive science or memory disorders had been able to thoroughly evaluate his amnesia, it might have been possible to sort out questions of capacity relative to his own current healthcare decisions, as follows.

1. Although Mr. G seems to have ongoing access to his long-term memories, which might include, for example,
 - A. Episodic memories about family relationships, experiences, traditions, and values and
 - B. Semantic memories, including general knowledge about the world, for example, general definitions of concepts like *quality of life*, *cancer*, *side-effects*, *benefits and burdens of treatment*;
2. Mr. G is demonstrably no longer able (at present anyway — the question of whether his capacity can someday be restored remains undetermined by the neurology team or memory disorder experts) to consolidate memories of his current diagnosis and prognosis.
3. Such abilities are directly relevant to the task of making decisions about whether life-sustaining chemotherapy treatments should be accepted or refused, including whether to pursue further diagnostic and prognostic information that might inform that choice.
4. In other words, even if Mr. G retains the ability to retrieve long-term semantic memories about the general meanings of concepts like *quality of life* and *benefits and burdens of treatment*, he cannot form new memories to consolidate and process new diagnostic and prognostic information, in order to elaborate these general concepts specifically for use in making current and future decisions.

According to this reasoning, the above proxy appointment can be accepted on justifiable grounds (assuming no other concerns considered above remain, in which case another proxy could be sought), and obligations relating to the other components of informed consent — disclosing information, ensuring understanding and voluntariness, obtaining consent — transfer to Mr. G's proxy. Thus the team must now focus on informing Mr. G's brother and ensuring that he understands the information shared, so he has the best chance of applying his existing knowledge of Mr. G's core values, beliefs, and preferences to determine what Mr. G would want in his current condition. In this scenario, it is no longer repeatedly necessary to inform Mr. G of his cancer diagnosis and prognosis (he appears to have some insight as to his amnesia, which is not out of keeping with the brief descriptions of AA patients above). It is also not necessary to seek "consistency" of his expressed historic or current preferences as applied to a diagnosis he cannot retain, or to "theoretical situations" that he is unable to fathom, despite the fact that other retained abilities make him seem "quite lucid and capable of decision making." Continuing to treat Mr. G as if he possesses specific capacity relative to accepting or refusing possible life-prolonging treatment, when it has been established that he does not, is paradoxical, and merely serves to confuse Mr. G, and perhaps also his family and healthcare team. Thus, if

the healthcare team and others had a better understanding of Mr. G's own precise amnesia syndrome (here using AA as an example for discussion purposes only), per appropriate testing and evaluation, Mr. G's apparently conflicting memory abilities and disabilities could be put into better perspective, clarifying the assessment of capacity, the appointment of a proxy, and the making of treatment decisions.

The lingering questions about whether Mr. G's brother is a "true proxy, speaking in '[Mr. G's] voice'" (although, as stated, this might be a rather high standard for any proxy to achieve) seem rooted in legitimate questions about whether Mr. G's brother has been given adequate information about Mr. G's diagnosis and prognosis, how that information was framed, and whether Mr. G's brother himself adequately understands that information. Ensuring that information is disclosed and adequately understood — transferred here to Mr. G's proxy — remains an obligation of informed consent. As such, it would be in keeping with ongoing autonomy-based obligations to Mr. G (via his proxy), and moreover ongoing beneficence-based obligations to Mr. G, for the healthcare team to explore further with Mr. G's brother what he understands of the core diagnoses and prognoses, and to ensure his adequate understanding of possible "benefits" and "burdens" of treatment, possible applications of "quality of life" (carefully avoiding subjective biases as possible), and how and why these concepts might fit with Mr. G's pre-existing values, beliefs, and preferences. This is, after all, the precise ability Mr. G himself lacks (despite his own continued access to long-term semantic memories enabling him to report the generality, "I have always said I would not want to go through all that. It's really about quality of life and who wants to go through all of that"). These concepts and values must be newly considered, explored, defined, and weighed by Mr. G's proxy relative to Mr. G's new diagnoses and prognoses. It is particularly important to ensure that information is disclosed and adequately understood by Mr. G's proxy, given how "adamant" the proxy is, not only in refusing life-prolonging treatment, but in refusing further work-ups and information that might normally more fully inform this choice, especially considering the high costs either way to Mr. G.

These clarifications can perhaps be better understood by reflecting for a moment on Harvard psychologist and memory researcher Daniel Schacter's reminder, "memory involves more than just our remembrance of things past."¹¹ Rather, Schacter explains that our autonomy is reshaped as we go through life, making and remaking memories projected into the future, depending on how we convert the fragmentary remains of experience into the autobiographical narratives that endure over time, and constitute the stories of our lives. Mr. G's brother and proxy is now shouldering the burdens of uncertainty in this case study, and the healthcare team can only help him and Mr. G as best they can, by ensuring adequate information is disclosed and the proxy adequately understands the information, and gives voluntary consent.

NOTES

The quotations at the beginning of this article are from Rebecca Rupp, *Committed to Memory: How We Remember and Why We Forget* (New York: Crown Publishers, 1998), 8-9 and xv.

1. T. Beauchamp and R. Faden, *A History and Theory of Informed Consent* (New York: Oxford University Press, 1986), 287.

2. Also, this gatekeeper and these latter components should not be confused, as capacity and understanding in particular often are, and may have been in this case.

3. It is worth noting, however, that the authenticity of the portrayal of AA in the movie *Memento* has been debated. On the plus side, one clinical neuropsychologist judges it to "accurately describe the problems faced by someone with severe anterograde amnesia," S. Baxendale, "Memories aren't made of this: amnesia and the movies," *British Medical Journal* 329 (2004): 1480-3, p. 1482. On the negative side, one neurobiologist has declared it to be "very unfaithful," and another expert in memory disorders regards a core misunderstanding reproduced therein to be a "howler,": J.R. Minkel, "Gene Expression: The Brain's Memory Code," 29 December 2003, www.gnXP.com/MT2/archives/001537.html, citing UC Irvine neurobiologist James McGaugh; L. Spinney, "Forgetfulness of Things Past," *Guardian*, 29 April 2004, www.film.guardian.co.uk/

features/featurepages/0,,1205937,00.html, citing Sergio Della Sala of Edinburgh University. Moreover, the former clinical neuropsychologist and latter memory disorders expert both regard Walt Disney/Pixar's animated blue tropical fish Dory in *Finding Nemo* to be "the most neuropsychologically accurate portrayal of a [profound] amnesic syndrome" and "top of . . . amnesia class" in the movies, Baxendale, "Memories aren't made of this: amnesia and the movies," p. 1483; Spinney, "Forgetfulness of Things Past," citing Sergio Della Sala of Edinburgh University. Another commentator, a Los Angeles film critic who completed an impressively comprehensive analysis of the film, notes the film's "huge inconsistencies" with the "rules" of anterograde amnesia (as explained by the film's main character, an insurance investigator who previously researched this very amnesic syndrome that he himself now suffers, ironically "ruthlessly [denying] the [earlier] man's medical claim"). Klein surmises that the film's director may be injecting these inconsistencies on purpose, to pose an additional devilish puzzle for his viewers, but complains that "to build the plot around [these inconsistencies with the rules of AA] without giving us some hints seems like dirty pool," A. Klein, "Everything You Wanted to Know About 'Memento'," *Salon.com* 28 June 2001, www.archive.salon.com/ent/movies/feature/2001/06/28/memento_analysis/.

4. Spinney, see note 3 above, p. 6.

5. One cell biologist regards working memory as a "more complex entity . . . [enlarging] upon the earlier and simpler concept of short term memory," but the relationship between short-term memory and working memory is still not well worked out. R. Rupp, *Committed to Memory: How We Remember and Why We Forget* (New York: Crown Publishers, 1998), 61, 65-6. See also D. Schacter, *Searching For Memory: The Brain, The Mind and The Past* (New York: Basic Books, 1996), 82-8.

See also D. Pendick, "Memory Loss at the Movies," *Memory Loss & the Brain: Newsletter of the Memory Disorders Project at Rutgers University*, 2002, www.memorylossonline.com/spring2002/memlossatmovies.htm. Pendick makes another distinction, arguing that short-term memory — defined as "the bin in which we store recent experiences and perceptions for minutes to hours while they are 'consolidated' into more enduring 'long term' memories") is not in fact possessed by AA patients, who instead operate in the realm of working memory (defined in a more limited way as "the bin that holds experiences for [mere] moments to seconds . . . [meaning that such a patient] can hold a conversation as long as the other person doesn't go on speaking too long [so he] might forget where the conversation started and get confused [but, like the main character in *Memento*] maintains his intelligence, his ability to reason, make logical arguments, express his thoughts, read a map, or keep a telephone number 'in mind' long enough to dial it.")

6. L. France, "The Death of Yesterday," *Observer*, 23 January 2005, www.observer.guardian.co.uk/print/0,,5107999-110648,00.html.

7. National Academy of Neuropsychology, "Behavioral Neuropsychology: Amnesic Syndromes," 1997-1998, www.nanonline.org/nandistance/mtbi/ClinNeuro/amnesia.html. Causes of AA listed include: alcoholic Korsakoff Syndrome, traumatic brain injury, cerebral anoxia, tumors within or near the hippocampus, and dementia-related illnesses such as Alzheimer's disease.

8. S. Corkin, "What's New With the Amnesic Patient H.M.?" *Neuroscience* (20 February 2002): 153-160; pp. 154-6, 158-9.

9. W.B. Scoville and B. Milner, "Loss of Recent Memory After Bilateral Hippocampal Lesions," *Journal of Neurology, Neurosurgery and Psychiatry* 20 (1957): 11-21; p. 17.

10. Rupp, see note 5 above, p. 88.

11. Schacter, see note 5 above, p. 5.