

Electroconvulsive Therapy and Memory Loss: A Personal Journey

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Summary: The cause for the significant gap between research and anecdotal evidence regarding the extent of some memory loss after electroconvulsive therapy (ECT) has never been adequately explained. A patient's development of awareness and self-education about her severe side effects from ECT raises questions regarding many current assumptions about memory loss. ECT-specific studies, which conclude that side effects are short term and narrow in scope, have serious limitations, including the fact that they do not take into account broader scientific knowledge about memory function. Because of the potential for devastating and permanent memory loss with ECT, informed consent needs significant enhancement until advancing research on both improved techniques and on better predictive knowledge regarding memory loss progresses to making a greater impact on clinical applications. Follow-up care and education in coping skills need to be a regular part of ECT practice when patients do experience severe effects.

Key Words: Electroconvulsive therapy—Memory loss.

INTRODUCTION

Occasionally, I feel bitter. More often, it is a sadness, a sense of a deep loss that may not even have had to happen. It is a grief that keeps deepening over time, because there is hardly a week that goes by that I do not discover yet another part of my life that is lost somewhere in my memory cells.

Despite that, I remain unflagging in my belief that the electroconvulsive therapy I received in the fall of 1995 and then the spring of 1996—33 treatments, initially unilateral and then bilateral—may have saved not just my mental health, but my life. If I had the same decision to make over again, I would choose ECT over a life condemned to psychic agony, and possible suicide. Like a heart patient who has to choose the risks of surgery over the risks of heart attack or stroke; like the cancer victim who must choose the horrible side effects of chemotherapy over certain death to the disease—I live with and accept the price I paid to break the stranglehold of a seemingly intractable and severe depression.

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Perhaps it is all as simple as that: a medical cost-benefit analysis between treatment with its side effects, or remaining with alternate, less effective treatments. As with any other illness and its treatments, new research and developments that reduce risks and increase effectiveness do not always trickle down to the front lines of practice as quickly as they should.

ECT, however, is different in several critical respects. It has a history of extended public controversy that may well exceed that of any other longstanding medical treatment, a controversy that would appear unjustified by the treatment's clear efficacy, or even its early abuses. There is an aura of dishonesty about the side effects: discrepancies between official positions and numerous personal testimonies of more severe problems that are discounted or left unexplained.

My long-term memory deficits far exceed anything my doctors anticipated, I was advised about, or that are validated by research. To the contrary, either I am one in a thousand, a complete anomaly, to be able to document memory loss still remaining after 3 years and extending as far back as incidences eight to nine years ago, or the profession in general, after all these years of treatment with ECT, has still failed to identify and come to grips with the true potential risks.

While the more distant incidents may be random events, they are hardly insignificant ones: hosting and driving Mother Teresa for a full day visit to Los Angeles in 1989; the dinner reception for my National Jefferson Award in Washington, D.C., in 1990, where I met and sat beside my co-honoree, General Colin Powell; my brother's wedding in 1991—the list goes on, and keeps growing as people bring up references to the past in casual conversations.

Human memory seems to me to be one of the most precious aspects of our personality, since our memories are so critical to who we are and how we see ourselves and others. The memories of our past give us an understanding of where we fit in the world. I have experienced more than a "cognitive deficit." I have lost a part of myself.

THE JOURNEY OF AN EXPERIENCE WITH SEVERE MEMORY LOSS

The greatest anxiety about ECT has been described as the fear of memory loss (Bernstein et al., 1998). As Fink (1997) has noted, "The effects of ECT on memory and cognition contribute to public fears. ECT does affect the mind—that unique and delicate essence of our individuality that distinguishes one human being from another..."

It has taken several years for me to gain the kind of perspective on coping with my memory loss to allow a reflection such as this. The lack of any referral, follow-up care, or general information forced me both into my own efforts at research and my own struggle through the process of developing coping skills. As I look back now, almost 3 years since the start of my first series of treatments in September of 1995, I recognize that while gaining information ultimately helped in understanding, it also contributed to feelings of anger and betrayal that complicated phases of the recovery process.

I had been easily treated on medication for two prior episodes of depression in 1987 and 1989; my 1993 relapse had failed to respond to medication trials. ECT was presented as an uncomplicated and low-risk alternative, with only short-term memory effects to be concerned about.

Thus in the most immediate time frame after the final course of ECT in June of 1996

I was not particularly anxious about my memory loss. I "knew" from my doctors that my memory would mostly recover within 6 months, so I was very casual, almost flippant, about the side effects. Throughout that fall, my mood was fairly positive, and since it was a temporary effect, it was something to make fun of among friends: jokes from them, "You mean you don't remember that \$500 I loaned you?" or my mock insistence that it was their memory that was impaired, not mine, "I know for a *fact* that we've never been to this restaurant before."

Perhaps more important to my light attitude was the fact that I had no concept of how much information was gone from my past. It may seem obvious, yet it becomes a truism that may cast one bit of light on those impairments that are not reported by patients when research follow-up is only done in the first few months: You cannot be aware of something that is missing. It is only through the gradual process of hearing others talk about the miscellany of life that one rebuilds the knowledge, though not necessarily the memory, of events past. Until that process develops, the vacuum remains unknown and unknowable, so the panic and sense of loss do not occur immediately. When, as in my case, follow-up assessment is not routinely done, the severe losses may remain unknown to the treating physicians, and any care for coping is thus left undeveloped.

It affected my relationships with newer, more casual friends in a very different way. I simply did not remember the status of our relationship. In addition, the gap in time caused by the gap in the corresponding memory period made it seem like far more time had passed than was real. I was not prepared to discuss ECT with them, and without being able to explain uncertain overtures, I was not comfortable approaching them. Most of these friends knew basically about my illness, and would have waited to hear from me, not wanting to intrude. The relationships with these people basically drifted away. Public stigma over mental health has been reduced somewhat in recent years, and it is not difficult for me to reveal my disability anymore, but ECT remains in a class of its own. I have encountered stunned silence or even horror.

As the 6-month marker came and went with only partial recovery of my recollection for past events, my focus began to change. I was again not doing as well emotionally, which affected my positive attitude. In addition, some mental health advocacy groups that were hosting a disability information day at the Vermont statehouse had asked me to put together a revised fact sheet on ECT. Feeling inadequately prepared, I did some superficial research.

I was completely stunned by the discrepancies I found. While multiple studies found any long-term amnesia to be extremely rare (as summarized by Sackeim (1992), informal accounts, advocacy group information, and newspaper exposés described extensive and broad-based risks (Breggin, 1979; Cauchon, 1995; Vermont Protection and Advocacy, 1996). Hearing claims such that ECT caused brain damage were terrifying to a layperson when discovered without yet knowing the questionable professional standing and credibility of the sources.

I had in fact experienced significant and long-term impairment that I could easily distinguish from ordinary memory fallibility. Yet as I reviewed what I had found, it seemed clear that comprehensive efforts to assess long-term adverse effects had not been made. I found repeated acknowledgment that more research was needed on memory loss (Culver et al., 1980; Weiner, 1984; Kaplan and Sadock, 1989; Calev, 1991; Sackeim, 1992; Devanand et al., 1994).

Despite the controversy and lack of a secure foundation in research, there appeared to be a general consensus among most experts, writers for lay audiences, and practitioners, which all grossly minimized my experience: 1) that virtually all impairment is reversed within 6 months, and 2) while there may be evidence for rare cases of more permanent loss, such loss existed only for spotty autobiographical memories from the few months before or after ECT (Squire and Slater, 1981; Frith et al., 1983; Kaplan and Saddock, 1989; Calev et al., 1991; Janicak et al., 1991; Papolos and Papolos, 1992; Sackeim, 1992; Ablow, 1993; Salmans, 1995; Sobin et al., 1995; Coleman et al., 1996).

Anecdotal evidence suggesting greater permanent impairment was often dismissed on the basis that other causes were more likely: the effect of depressive illness itself, the heightened sensitivity to loss being used to misidentify normal memory loss caused by such processes as aging, and exaggeration of effects for reasons such as perceived secondary gains of having a cognitive disorder (Squire and Slater, 1983; Weiner, 1984; Weiner, 1989; Sackeim, 1992; Sobin et al., 1995; Coleman et al., 1996). Research such as that of Squire (1981) and Weiner et al. (1986) suggesting the possibility of more persistent deficits, as I would later learn, was considered no longer persuasive since it was based upon comparisons with outdated sine wave technology, failed to take into account the independent effects of depression, or was considered methodologically inadequate (Calev et al., 1991b; Devanand et al., 1994; Coleman et al., 1996).

As shaken as I was to suddenly feel like an involuntary game piece in the center of a quasiscientific, quasipolitical debate, I was also intrigued. My discussions with family and friends shifted from jokes to serious efforts to pin down information. I began to initiate many more questions about events of the past, and thus to learn more and more about the extent of my amnesia. I also began to recognize the variation in some of the ways I was either recalling, or possibly falsely recalling, different memories. At times, particularly early on, full recall clearly did occur, whether spontaneously or based on a reminder stimulus despite an initial gap. There are other major past events for which memory has never returned. In the summer of 1992, for example, 3 years before my first treatment, my parents built their retirement home adjacent to my log cabin. Based on the skills I had learned building my own cabin, I volunteered to do all of the plumbing for their six-bedroom, six-bathroom, three-story house. I have several photos of my father and myself triumphantly completing the first basement main hook-up. Yet I have no recall whatsoever of this massive undertaking.

Between retrieval and total loss lies an unknown cross-over range of partially filled-in, partially reconstructed, or possibly completely "created" memories through external information planting, which then becomes mistaken as an actual memory. These obviously are very difficult to distinguish. Shortly after my last treatments in June of 1996, I remembered some sense of importance attached to something having happened in Oklahoma City. When I asked about it, my brother filled me in about the events a year earlier, and it was all completely new to me. As time went by, however, and I have seen pictures of the tragedy, it seems to me that I have regained vague memories—but only those which correspond to the pictures.

Similarly, in March of 1996, friends from as far away as Missouri gathered for a weekend reunion at my house for my 40th birthday. I have a full photo album: the evening dance, visiting the sugarhouse, the morning pancake breakfast. I had been relatively sure that I remembered the weekend, despite it being sandwiched between my fall and spring

ECT series. But then I was told about all the fun we had sledding that weekend, the great airline fiasco one family endured, the serious hand injury a friend incurred on the rope swing—there are no pictures of these events, and it has become clear that the only memories I have are of those things that do exactly match the pictures. Are the memories completely suspect as false creations, or is a photo trigger more effective than a verbal trigger in bringing back actual memories?

The basic research I had uncovered on ECT side effects made no effort to distinguish among the many variables of human memory. It is relatively clear that the brain both routinely loses or has a break in the process of retrieval from long-term to working memory (Harrell et al., 1992), but also creates memory. Fiush (1996) points out the degree to which “we can be misled about our own memories” (see also, Crowley and Underwood, 1998; Payne and Blackwell, 1998). I had some limited familiarity with the work of Elizabeth Loftus on memory from research I had done years earlier as a young lawyer assisting in a murder case involving mistaken identity, and I knew the field had been pioneered when the issue of retrieved versus falsely created memory first became a debate in eyewitness identification cases and then in childhood sexual abuse prosecutions several decades ago, as noted by Alpert (1996). I had been fascinated then by what I learned about the brain and the inherent unreliability of our memory mechanisms.

As time goes by, earlier memories cued back after ECT seem more and more real to me, regardless of whether they ever were. Schooler (1996) observes that information integrated into memory can be held “with as much confidence as real memories” (see also Hirt et al., 1998; Moscovitch, 1989). This question is not a part of the studies assessing recovery of memory from ECT. For instance, while Sackeim (1992) summarizes the generally accepted description of the effects of ECT as being that, “The retrograde amnesia will often show a more gradual reduction, with substantial *return of memory* for events that were seemingly ‘forgotten’ immediately following the treatment course,” (emphasis added), memory researchers such as Toglia (1996) point out instead that “The constructive nature of memory is sufficient to create recollections that are essentially entirely false” (see also Schooler, 1996).

The lack of connection between these fields also meant that I began a search that would last years to try to get memory assessment and help, when the resources should have been well known and available—and I should not have been the one to have to identify the need.

After that first significant experience of looking at basic ECT research, I became more anxious to gain a fuller understanding of what had happened to me. By the spring of 1997, I was in a more stable remission, and became eager to learn more about what was and was not known in whatever additional research I could track down. In doing so, I came to understand more fully the disparity in my case from standard statements about ECT, and I was increasingly frustrated in seeing how limited the data seemed on what the more serious effects could be.

Improved research was clearly not an easy task, particularly with the difficulty of devising tests to confirm the often random or isolated memory losses reported by many patients. The personal nature of perceptions, the complexity of human memory, and the processes of encoding, retrieval, and normal forgetting (Kellner, 1996; Cowley and Underwood, 1998; Payne and Blackwell, 1998), and the question of whether at the time testing is typically done the patient has gained an adequate sense of the degree of memory

loss (Coleman et al., 1996) are only part of the challenges. There is also the difficulty in pinpointing what an individual's prior memory would accurately recall, particularly in a person with depressive symptoms (Sackeim and Steif, 1988; Sackeim, 1992; Sobin et al., 1995) (including the possibility that those with specific preexisting impairments are more at risk for more severe impairments, as well as more likely to have subjective complaints) (Sackeim, 1992; Sobin et al., 1995; Coffey, 1996). Finally there are the limitations of scientific research in general, as summarized by Sackeim (1992), including the use of tools with inadequate psychometric properties, the issue of the breadth of cognitive functions evaluated, the need for a wider range of ecologically valid assessments, review of the aberrant processes involved, and the limitations of intergroup comparisons pooling data across individuals, so that outliers with more persistent deficits may be missed since "within any research program such individuals would be too rare for meaningful analysis," or so that effects with a low incidence of occurrence will wash out (Weiner et al., 1986a).

Despite the challenges, it seemed incredible to me that more had not been done. How could it be possible that ECT had been practiced for so long without a better grasp of its side effects? How could the research be so apparently limited in its focus and assumptions? Why was there no greater effort to understand *why* ECT caused cognitive losses, how often they occurred, and how severe they might be? Perhaps more than anything, how could I be experiencing what I was, if all these experts were saying it wasn't so? I felt that I was being mocked by science.

As the year continued, I began to care much more intensely on a deeply emotional level about what had happened to me. To what degree was I a different person, someone I did not even really know, because I had lost so much memory of my past? Finding out more and filling in the gaps suddenly became an urgent matter, and I pressed family and friends to distraction about events I might remember. The more I heard, the more I realized what I had lost, as one topic led to another. In the period between my two treatment series, and for 1 to 2 years before the beginning of the first, it became clear that I had near-total retrograde amnesia. It was more spotty but still significant for years earlier than that. Every new incident continued to shake me, and I did not know how to cope with these gaps and my reactions.

By that fall, a year and a half after ending ECT, I had finally regained a more stable period of remission, and I began to work on my own to develop a more gentle and constructive perspective. It occurred to me that there were times I needed to remember that I had amnesia—specifically, for one, when asked about my medical history. I had noticed a series of tiny bumps on my forehead and thought they were pimples, then later saw in a mirror that it was a scar from stitches. I had to ask my doctor to trace back through my files to find the record of a fall and stitches in 1994.

I needed to remember not to deny events based on my own belief—not to forget that I might have forgotten. I have to keep vigilant to not prejudge someone as lying or misleading simply because I forgot that the fault could have been my memory. Early on, I attacked my local bank for negligently bouncing a check. They had to show me my own signature before I believed that the check came from an account that I had closed. I had to alter my everyday thinking patterns, have a suspicion towards every recall. Sometimes it gave me a sense of being an outsider looking in to my own past world.

As I finally began to reach an equilibrium, an acceptance of what happened and how

to learn to live with it, I have become more relaxed in dealing with everyday situations that continue to arise. I find people almost universally helpful when typical encounters occur.

Woman on street (*in chance meeting*): "Anne! How wonderful to run into you. How are you?"

Anne (*rapid assessment: This is a person once well known, not a passing acquaintance who can be handled by bluffing through a conversation*): "Well, hello! Listen, I need to fill you in on something. I've been ill and a treatment I received has blocked my memory for several years back. I have to be honest. I have no idea who you are."

Woman: "Oh! Well, I'm Catherine S., from our time working together in New York in 1986."

Anne (*much relieved*): "Of course! Seeing you here out of time and place just threw me off. I remember now." (As well I did, from 9 years prior. I had just never expected to see her here in Burlington.)

Anne (*continues*): "Well, it's great to run into you here. What brings you to Burlington?"

Catherine: "I live in Burlington, remember?"

Anne: "No, I never knew that."

Catherine: "Well, actually, you did know that. We've had lunch together here several times over the past few years, and I've been out to visit you. It must be that treatment you mentioned."

I have never had a negative reaction to this kind of honesty. I do not necessarily go into a further explanation if I am having a passing encounter, but I do feel free to do so when there is time and supportive interest from the listener.

Despite acceptance and a growing comfort level in talking openly, despite the emotional outlet for anger through the development of my academic interest, and despite working through the experience of losing part of my sense of self, I remain bothered by a sense of incompleteness. It is obvious that if there is a serious side effect after heart surgery, there is follow-up intervention. The patient is checked for residual bleeding.

I had not been checked for residual bleeding. I feel left hanging—that nothing was ever comprehensively tested, recorded, or analyzed by the psychiatric profession and those involved in my care to evaluate my side effects: not just to intervene and to help me, but also to learn from my results. This should be routine when initial response shows significant cognitive impairment, as mine did. If it is done more adequately in other situations, the information, regardless, has not been collected and shared. No wonder the establishment has a different sense of the side effects. They don't ask.

I think that this lingering feeling of abandonment of care by the psychiatric profession, both as an individual and in a deeper sense on behalf of my peers, is strongly related to the part of me that still feels so damaged by my memory loss.

CONCLUSION

My story is my own—what happened to me, and the care I did or did not receive cannot automatically be assumed to apply to the practice of ECT in the U.S.A. today or to the follow-up care delivered when severe side effects result. The broader existence of activist groups of former patients who, for whatever reasons, are disgruntled by their results

sufficiently to attack the treatment itself, should also contribute to giving pause as to potential adequacy of care explanations for the vitriol of their distrust. While such attacks may be poorly founded, they are part of a landscape that both interferes with a vital psychiatric tool and helps to illustrate the pressing need for an improved response.

My own experience, and the research I pursued as a result, has led me to three major conclusions regarding areas which should receive greater attention:

1. Make a more concerted effort to conduct research that can better explain the discrepancies between the "official" consensus and the reported experiences of those uncounted and unaccounted for "outliers" like me.
2. Reduce the gaps in clinical knowledge.
3. Improve information on side effects and resources for aftercare for patients.

Weiner's (1984) call for precisely the *type* of information on the "nature, incidence and severity of possible persistent memory deficits... [including] large, well controlled prospective studies with long term follow-up" that I found so lacking and distressing, remains unanswered.

Research on improving efficacy and reducing side effects in the future is not the same as evaluating past and current status, and despite the efforts of the American Psychiatric Association (see 1990 Task Force report) to increase knowledge about the more potentially severe range of effects, there remains a near constant circulation of highly uninformed descriptions denying a problem [see, for example, Internet Web public medical information page stating, "The memory disturbance that has alarmed the public is relatively minor and temporary," (Mental Health Infosource, 1999)]. Paul Fink is quoted in a practitioner's study guide as saying during a practice guidelines discussion, that "The biggest reason people don't want to use it [ECT] has to do with memory loss. I am of the school that believes there is a transient confusional state and no memory loss" (Study Guide on Practice Guidelines, 1994) [statement later privately withdrawn (P. J. Fink, personal communication. Dec. 14, 1998)].

The juxtaposition of misstatements about the extent of possible memory loss continues the perception that side effects are being described dishonestly, to one extreme or the other. It is a part of what makes ECT different from other medical care, since the discrepancies "keep the controversy raging" (Center for Mental Health Studies, 1998), can be a factor in refusing treatment, and have resulted in public efforts to have it banned or to have informed consent statutorily defined (see impact upon state practices, Herman et al., 1995; and samples of legislation passed or pending, Cal. S.5326; Col. R.S.13-20-400; Texas 578.000; Vermont House of Representatives bill, H.12, 1999). My attempt at gathering accurate information went far beyond a typical patient's, yet I gained little more than the fear and confusion generated by grossly conflicting and limited data.

There are also serious gaps in clinical knowledge. If the treating psychiatrist is not fully aware of the degree of memory effects, he or she may also not recognize how critical the latest developments in techniques may be. I cringe when I review the ongoing research evolving, and recognize that even without an explanation for how and why extensive deficits do occur, they might have been avoided for me with insights on appropriate treatment. Practice levels currently often fall short of scientific updates, with Sackeim (1998), for instance, reporting that an estimated 30% of practitioners are still using the

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substantially higher-risk, pre-1985 procedure of dosing at a uniform, high level. Other practices exceeding recommended guidelines are documented by Reid et al. (1998). Thus my medical cost-benefit analysis in accepting ECT treatment was skewed from the start by the fact that the existing professional statements on potential risks did not match the actual risks presented by current mainstream practice.

The final issue is the information provided to the patient. As Sackeim (1992) notes, even though the reasons for the discrepancy between objective testing and subjective reports are unknown, "...in informing patients about ECT, it is important to relate that a few individuals report profound and long-lasting cognitive impairment that they attribute to this treatment modality." Kellner (1998) appropriately suggests that the key to improved informed consent is "a middle ground that does not appear defensive": disclosure both of ECT's powerful, lifesaving effects and its serious side effects, dealing with it in a way that eases apprehension and allows an informed choice between typically brief impaired functioning and a return to health (Kellner, 1996). While this goal has been clear at least since the 1990 Task Force report of the American Psychiatric Association, his belief that, "Nowadays, we *do* tell patients what to expect and everyone is better for it," (Kellner, 1996) is not yet a universal reality.

Because ECT involves a series of treatments during which the cost-benefit ratio continues to change and the patient's ability to participate in informed decision-making often continues to improve, while at the same time, memory of the original consent may become impaired (Consensus Conference, 1985), potentially contributing to patient perceptions that side effects were worse than expected (Bernstein et al., 1998), a better record available later to the patient of his or her own participation in the consent process (such as offering to audiotape or videotape, or having a family member or friend present), as well as written information for a follow-up cognitive assessment plan if needed, should also be provided (as an example of work with coping skills, see Harell, 1992). None of this was offered to me, and it was the lack of information, as much as the actual effects, which made recovery so difficult.

In addition, as Kellner (1996) so well summarizes, "Preparing a patient for the predictable, expectable, and largely stereotyped effects of ECT on memory and other domains of cognition is honest, necessary and helpful. It leads to realistic expectations for the treatment, and can help the patient and family prepare for the post-ECT period. Disappointment and fear are decreased and some practical steps towards restoration of memory (coaching, list-making and 'filling in' by family and friends) can be planned."

Without these advances—more comprehensive research regarding causes and rates of the most severe instances of memory loss, better transmission of new clinical information to practitioners, and more comprehensive, accurate information and follow-up for patients—a vital tool in the battle against life-threatening affective disorders will remain underutilized. It is a major social loss that should not have to be that way.

If sharing my own experiences of successful treatment but deeply troublesome side effects can help in that cause—if my voice is heard, and heard to speak for others like me—then my own sense of damage and abandonment will be assuaged. It will give my experience a value in the lives of others. It will not help my own memory to return, but it will ease the pain of the feeling that the damage may have been unnecessary to achieve the results.

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