

## Chapter 9 The Swinging Pendulum: The Effects of Politics, Law, and Changes in Medical Culture on ECT?

Reform movements have punctuated the history of psychiatry. From the celebrated loosening of the chains of the inmates of the Bicêtre Asylum in Paris by Philippe Pinel in the 1790s, to the policies of non-restraint in the mid-nineteenth century, and to the revisions of the committal laws during the twentieth century, practices and theories of mental illness have responded to broader contexts of social change. These reforms are often lumped together with the convulsion that struck psychiatry during the 1960s that has been termed “antipsychiatry,” but 1960s antipsychiatry was fundamentally different to anything that had gone before<sup>1</sup>.

### **Antipsychiatry**

Previous reforms focused on conditions within the asylum and did not threaten medical claims that the conditions being treated were mental illnesses; indeed reform essentially involved a medicalization of what previously had been seen as social problems. Antipsychiatry in the 1960s, however, hinged on the notion that mental illness did not exist, or at least not in the form that psychiatrists claimed. The antipsychiatrists argued that, in fact, society itself had gone mad and that those suffering from mental illness were only its most apparent victims.

From our vantage point in the twenty-first century, this is an argument that the antipsychiatrists seem to have lost. Today increasing numbers of people take psychotropic medication of one sort or the other, Ritalin, , Valium, Zoloft, just to name a few. Increasing numbers of illnesses are identified and listed in diagnostic manuals such as the Diagnostic and Statistical Manual for Mental Disorders, 4<sup>th</sup> Edition, *DSM-IV*. Media coverage of all topics related to mental illness and consumer advertisements of psychotropic medications has exploded in recent years—clearly, the public places some notion of reality to the idea of mental illness. But arguably the claims of anti-psychiatry have been proven rather than disproven by these developments: While the headline claims of 1960s antipsychiatry focused on the acutely mentally ill who were committed to asylums, in fact, the real concern was for the rest of society who for the first time were exposed on a mass scale to the attentions and ministrations of psychiatry.

There was a deinstitutionalization of the hospitals began in the 1950s with the development of chlorpromazine and the psychopharmacological revolution but in fact there are no fewer patients in service beds now than there were fifty years ago. Before the Second World War, few people were at risk for being committed to an asylum and most knew no one in professional treatment for mental illness. Now we all know many people being treated with Prozac, Paxil, and Zoloft, and children from the age of two to seniors of the age of 102 are likely to be on one or another of these medications. There has been a tripling of the rates of detention to psychiatric facilities, and a fifteen-fold increase in the number of patients who are admitted to a mental health service bed even in remote parts of Britain which, compared with the United States, are light in service

provision for mental illness.<sup>2</sup> Arguably those who were really deinstitutionalized were psychiatrists and other mental health therapists rather than their patients.

It was a recognition of this extension of the psychiatric reach that motivated the anti-psychiatrists of the 1960s, although in focusing on ECT and the seriously mentally ill they missed their target. The medical doctors who had previously run the asylums, the Alienists, had worked secluded within the asylum walls, from the 1960s onwards were increasingly likely to serve as office psychiatrists running community clinics. Access to the new pharmacology was by prescription only; in order to get help, people had to engage with psychiatrists in a way that they had not had to do before. Personal, private lives became the purview of psychiatrists. And who were they to make ethical judgments about aspects of an individual's life? How can we know whether their views are correct that certain behaviors were manifestations of psychological disorder rather than stemming from political concerns or social injustice?

We return again to the case of Randle McMurphy, the hero of *One Flew Over the Cuckoo's Nest* in Ken Kesey's 1962 book and in a 1975 film starring Jack Nicholson (see chapter 7). Kesey compares life on an asylum ward to the State in which we all live, an increasingly all-controlling, oppressive, Big Government that you have to protest against in order to survive. McMurphy then is punished for bucking the system; the ECT and later lobotomy he receives is a means of quashing rebellion and ensuring conformity. But the ultimate message was that if this can happen to someone like Randle McMurphy, it can happen to you. As Kesey makes very clear from the start, McMurphy does not have mental illness in any traditional sense. Rather he feigns mental illness to escape a jail rap. This anticipated a famous experiment undertaken by sociologist David Rosenhan in the late 1960s, in which volunteers posed as mentally ill and had themselves committed in order to experience life through the lens of psychopathology. It turned out to be frighteningly easy to fool medical staff and get detained in hospital, and indeed, in some cases it was difficult to get out of hospital afterwards.<sup>3</sup> The message was that psychiatrists did not know what they were doing and there was little that could stop them from doing it to almost anyone they chose.

The anti-psychiatry movement of the 1960s and early 70s fed the currents of cultural revolution in the West. Civil rights for African Americans, equal rights for women—a deeper meaning of democratic process took hold with new intensity. Where democracy before referred to the ability of people to cast a vote, now women organized to resist the colonization of their minds by men, and demanded an equal voice in the processes of government, in the ministry of churches, and in equal opportunities at work and within the law. It was a time when ethnic groups challenged the hegemony of the white elites of Western countries and argued that the acceptance of established views risked an internalization of white imperialism. Teenage rebellion was seen as resistance by the young to having their minds manipulated by their elders. Against the backdrop of World War II, the Cold War, and the Vietnam War, this resistance to the “wisdom” of a previous generation not only made sense but felt like a necessary struggle for survival.

Many of the most heated moments of protest and outrage took place at universities. In Paris and Tokyo, students marched on the universities, particularly medical departments of psychiatry. In Paris, the offices of Jean Delay, the discoverer of chlorpromazine, who also had worked prominently on the shock therapies in the early phase of his career, were ransacked and occupied for three months. More than anyone else in Europe, Delay was the symbol of psychiatry's new physical therapies. He was forced into retirement. The department of psychiatry at Tokyo University was occupied for ten years and all research there came to an end. Hiroshi Utena, the chair of the department, who was closely linked with research on the use of physical treatments, was also forced to retire.<sup>4</sup>

In the United States, as in Kesey's novel, anti-psychiatry involved a much greater element of protest against the State than it did in Europe and Japan, and student demonstrations in the US were linked to activism against the Vietnam War. The State was the ultimate source of malfeasance, corruption, and conflict of interest. Indeed, the notion of a conflict of interest was born in the 60s. Today we use the term to refer to a supposed corruption of research by private interests; in the 1960s and 70s the most obvious and threatening conflicts of interest were perceived to be the funding of research and education by the State.<sup>5</sup> Eisenhower's vision of a military industrial complex that threatens the liberty of all of us was the founding vision of concerns about conflicts of interest.

Psychiatrists and philosophers using psychiatry as a metaphor for the rest of society provided the public face of the upheavals. Ronnie Laing and David Cooper in Britain, Thomas Szasz, Erving Goffman, and Herbert Marcuse in the United States, and Michel Foucault and Frantz Fanon in France represented a cadre of influential thinkers who, in differing ways, offered visions of the confinement of deviance within the mental health system, of the need for individuals to resist therapy in order to stay in tune with their true self, and of the revolutionary potential of the oppressed. The disturbances in Tokyo erupted after Szasz and Laing visited the University in 1968.

In 1969 Szasz co-founded the Citizens' Commission for Human Rights (CCHR) along with the Church of Scientology. A key event in this founding centered on Viktor Gyory, a recent Hungarian immigrant detained at Haverford State Hospital in Philadelphia, where he was held in seclusion, forcibly medicated, and then given ECT. Szasz interviewed the man in Hungarian and was prepared to testify in court that Gyory was not ill, only unable to communicate in English. Rather than face a challenge to the laws on detention in Pennsylvania, the hospital released Gyory. CCHR and the Church of Scientology have since been the most sustained critics of psychiatry and especially of ECT, within the United States.

Szasz's vision that mental illness did not exist, and in particular that people designated as mental patients needed to assert their basic rights as citizens, was a key driver in American but not European antipsychiatry.<sup>6</sup> Taking inspiration from some of these themes, in 1970 The Insane Liberation Front was established in Portland, Oregon, and in 1971 a Mental Patients' Liberation Front in Boston, and a Mental Patients' Liberation Project in New York.

For a number of reasons, ECT became a key focus for all these groups. One reason was the simple salience of the treatment. Another was its symbolic value. A third reason was that some of the most coherent patients critical of psychiatry were individuals who had had ECT. But taking on ECT meant taking issue with a treatment that many thought clearly worked for severely ill patients, which was strategically a very different matter from taking on a treatment that did not have such a track record such as psychoanalysis, or the widespread and indiscriminate usage of SSRIs today. ECT, however, was more readily portrayed as a treatment that had been “survived” than psychoanalysis or Zoloft.

### **Survivors**

One of the first psychiatric “survivors” was Leonard Roy Frank. Frank had moved to San Francisco in 1962, where typical of the 1960s he dropped out, became vegetarian and developed an interest in religion. His Manhattan parents were horrified and had him compulsorily detained in Twin Pines Hospital in Belmont, California, for eight months from 1962 to 63, just as Kesey’s book was published. There, he was labeled a paranoid schizophrenic, and was first treated, fifty times, with insulin coma. He then had 35 electroshock treatments under the care of Doctors Norman Reider and Robert James.

Frank claimed sparse recollections from this period of time, and he spent five years trying to regain the knowledge that he believed the shock treatment had destroyed. He also began to learn more about psychiatry and in doing so, came across an early article by Szasz.<sup>7</sup> From there he gravitated toward the new survivor network that was emerging.

In 1972, Frank joined Madness Network News, which had been started by Sherri Hersh and David Richman in 1971. This was an early, pre-cyber version of the internet forums that psychiatric patients at the turn of the century would gravitate toward. In 1974, Frank and Wade Hudson founded the Network Against Psychiatric Assault (NAPA) in San Francisco. They became heavily involved in a campaign against ECT at Langley Porter Neuropsychiatric Institute aimed at prohibiting forced shock treatment, psychosurgery, and drug treatment in California. This eventually led to the passage of a statute in California that severely limited the use of ECT (see chapter 10).

In the course of this legal action, Frank accessed his medical records, and wrote up the story, which appeared in a book on shock treatment.<sup>8</sup> Nothing about these records provided good evidence for a diagnosis of paranoid schizophrenia, and both the records and Frank’s subsequent life suggested that he had had little more than a spell of injudicious usage of marijuana. Fired up, he began assembling the first edition of *The History of Shock Treatment*, a compilation of both academic and lay articles on various aspects of shock treatment and biological psychiatry.<sup>9</sup> In a review of the book, Szasz wrote: “What the rack and the stake were to the inquisition, what the concentration camp and the gas chamber were to National Socialism, the mental hospital and electroshock are to institutional psychiatry. *The History of Shock Treatment* is a carefully researched documentation of psychiatry’s final solution.”<sup>10</sup>

Leonard Frank's case was emblematic of wider trends. The period from the late 1960s through to the 1980s gave rise to a large number of patients' groups. Some were self-help groups taking their inspiration from Alcoholics Anonymous, which had been founded in 1935. A second type were the consumer groups who, as elsewhere in medicine, were concerned to ensure equitable access to decent facilities and the latest treatments.<sup>11</sup> These latter groups lay in a tradition of improving mental health care from Dorothea Dix to Clifford Beers.<sup>12</sup> But a third form were more political, taking their inspiration from Szasz and the antipsychiatry movement, and they saw it as their mission to protest against the abuse of individual rights that seemed endemic in psychiatric practice.

Another influential survivor was Judy Chamberlain, who in her early 20s had been hospitalized for depression in the mid-1960s. As a psychiatric patient she discovered she had no legal rights. This led her, in 1971, to co-found the Mental Patients Liberation Front in Boston. She later became affiliated with the Boston University Center for Psychiatric Rehabilitation<sup>13</sup>, which helped underpin a series of Ruby Rogers Advocacy and Drop-in Centers. These centers had a booklet outlining patients' rights, which even as late as 1994 stated: "Where is it possible to be imprisoned although you have not committed a crime? Where can you be held without bail and denied a trial? Where can you be deprived of your rights and stripped of your human worth? Where can you be put in solitary confinement, physically abused and given drugs whether you want them or not? In the American South in 1850s? In Germany in the 1930s? In a mental hospital in the United States in the 1990s?"<sup>14</sup>

Somewhat later, in 1980, NARPA (National Association for Rights, Protection and Advocacy) was founded by a group of patients' rights advocates, some of whom were lawyers, with a mission to promote the rights of psychiatric patients. Today this association is a mix of lawyers, non-legal advocates, and former patients. NARPA takes the view that mental health advocates were deliberately split into consumers on the one hand and survivors on the other by federal funding programs for the consumer side alone, and that this had led to a virtual elimination of the survivor movement.<sup>15</sup>

Similar movements developed in other countries. In Britain, a National Association for Mental Health (NAMH) was set up in 1947 from a number of pre-existing groups.<sup>16</sup> Initially building on thinking like that of Beers and Dix, this group was keen to see a provision of more psychiatrists, and helped sponsor the first social workers interested in supporting discharged patients in the community. Its approach to mental illness was almost identical to the position it took on mental retardation. In 1969, NAMH found itself under attack from the Church of Scientology, who accused it of being a tool of organized psychiatry. NAMH rejected what it perceived to be attempts at infiltration by Scientologists, but it also began to change character, and in 1972 was reborn as Mind, whose brief was one of explicit patient advocacy. For Mind, just as for NARPA and other groups in the field, ECT has been a key battleground. (see chapter 10)

From its birth antipsychiatry had opposed ECT. The possibility that this antagonism might be having an effect came into focus in an editorial in the *British Medical Journal* in

1975, which explicitly linked antipsychiatry and ECT: “Among the effects of the wide publicity given to criticisms of current psychiatric methods by the ‘antipsychiatrists’ has been an increasing reluctance to acknowledge the value of physical treatments such as electroconvulsive therapy – ECT.” “Other professions besides medicine are taking an increasing part in therapy... Rightly or wrongly these professions see their work as being to help people with problems rather than treat patients with diseases, and their weapons are psychotherapy, group therapy and alteration of social conditions.”<sup>17</sup>

### **Informed consent**

Another factor that distinguished Sixties-style antipsychiatry from organized opposition to psychiatry in the past—and the reason it has lessons for the rest of medicine—lies in the parallel evolution of informed consent

Physicians have informed patients for centuries about treatment options and have sought their written consent to procedures for over a century. So, on the face of it, the 1957 case of Martin Salgo against Stanford University would not be expected to offer anything fundamentally new or of far-reaching consequence to medicine. Salgo suffered permanent paralysis following a routine spinal X-ray at the Stanford University hospital and he sued in a case of argued negligence.<sup>18</sup> In finding for Salgo, the Court created a requirement for informed consent, which obliged doctors to disclose “any facts which are necessary to form the basis of an intelligent consent by the patient to the proposed treatment.”<sup>19</sup> This judgment enshrined the notion of informed consent for the first time, and fundamentally changed health care.

There were legal precedents for what happened in Salgo. A famous 1914 battery case resulted in a verdict that weighed in the later debate: “Every human being of adult years and sound mind has a right to determine what should be done with his own body. When a surgeon performs an operation without his patient’s consent he commits an assault.”<sup>20</sup> Battery (assault) is the tort involved when a person is touched or one’s privacy is invaded without one’s consent. Negligence is the result of a failure of due care, and it assumes that physicians are generally acting in good faith and that any injury is more accidental than intentional. In the case of negligence, a legally established duty must be breached resulting in an injury, measurable as damages, and this injury must be causally and proximately related to breach of duty. But until 1957 nobody had ever considered that a breach of duty might stem solely from not informing patients sufficiently.

There have been two historians of the informed consent movement. One, Martin Pernick, from the University of Michigan has argued that informed consent is not something novel, pointing to the prior existence of consent forms and the abundant evidence of physicians taking care to describe truthfully the hazards behind treatments.<sup>21</sup> Jay Katz from New York, and others, however, contest that these forms and any truth-telling imply informed consent, in that, before 1960 patients simply did not give permission to doctors in the same way they now do.<sup>22</sup>

The key question is what happened before 1960 when patients, informed of their risks, refused to accept a treatment. In the eighteenth and nineteenth centuries and through to 1960, physicians informed patients often in great detail, but the primary reason for doing so was in order to educate patients about their recommendations and therefore motivate them to comply with treatment. Patients were not informed about procedures or options on the basis that they might then opt not to comply. Benjamin Rush, an advocate of educating patients, argued in 1811 in “The Duties of Patients to Physicians” : “the obedience of a patient to the prescriptions of his physicians should be prompt, strict and universal. He should never oppose his own inclination nor judgment to the advice of his physician.”<sup>23</sup>

It was this position that underpinned medical willingness to deceive patients in their own interests if a doctor thought the patient might not be able to handle trickier, complex information, which could occur if he or she were not enlightened, well educated, or stable enough to deal with the emotional threat disturbing information might pose. This was a beneficence model, under which a physician’s responsibilities of disclosure and consent-seeking were linked to the primary medical obligation, which was to make the patient well. This primary obligation to help the patient surpassed any obligation to respect what would now be called the patient’s autonomy. If the truth were not going to be beneficial to the patient, then it would be unethical to tell the truth. Medicine was about instilling in the patient confidence, gratitude, and respect for the physician in order to enable the physician to do the best he could for acutely ill patients. It was not about treating the patient as an equal partner, in part because medicine until recently had few chronically ill patients who had the time and liberty to consider their options.

Few discussions of informed consent recognize that until recently, there was a lack of commonly accepted scientific knowledge that could be imparted to the patient. The information or evidence base that the physician used until the 1950s was primarily his own experience. There was not an objective body of evidence written up with non-physicians in mind to which patients or others could be directed. The idea that patients could be brought up to speed about a knowledge base that it had taken a physician a lifetime to acquire was considered bizarre. In contrast, the knowledge that we now think patients should be told is an entirely different and publicly available thing, stemming from published trials of treatments. Latterly the Internet, has further fed an appetite for medical knowledge in the hands of patients.

Faced with a directive from the Court that seemed to many physicians to come out of the blue, the medical profession, and not just psychiatrists, reacted with a mixture of hostility and bafflement.<sup>24</sup> It was deeply offensive to them to be told that their failure to seek consent meant little distinction could be drawn between the abuse of medicine in Nazi Germany and abuses in the course of research or clinical practice in the United States. A good example of the medical response came from Carl Fellner and John Marshall, who investigated why anyone would opt to donate a kidney, for example. They concluded that donation was an “irrational” process that failed to meet the requirements of informed consent<sup>25</sup>, with the implication that most of medical practice in such a context was equally absurd. As of 1982, seventy-percent of physicians in the United States continued

to define informed consent as providing information to the patient rather than indicating a mandate to seek explicit permission based on full disclosure. The Courts had instituted a radical break with tradition in 1957 that would take decades to feed through into day-to-day clinical practice.

### **Beecher and informed consent**

It is widely noted that with the rise of modern hospitals as sprawling institutions with corporate interests and the intrusion of ever more technology into the process of medicine, the relations between patients and physicians began to change. In the process, it became less acceptable for physicians to decide for patients without consulting them. But this new relationship did not come about simply because hospitals and machines were bigger, it stemmed in part from the availability of a new, public form of research evidence from randomized controlled trials (RCTs) .

The issue came to a head in 1966 in a *New England Journal of Medicine* article on informed consent written by Henry Beecher, a professor of anesthesia at Harvard.<sup>26</sup> Beecher outlined a series of research practices in some of the best-known hospitals in the country and undertaken by some of the most distinguished clinicians and researchers. In twenty-two separate research studies, patients who thought they were receiving normal clinical care were, in fact, research subjects and they were receiving clinical interventions that were quite problematic. No one study was singled out as involving poor practice as such, but their combined weight indicated that in some cases, treatment-related injuries had been inflicted on patients who were unaware of the risks. Patients who had trusted their physicians had become research subjects without being aware of it. There was an outcry. Within a year the FDA, NIH, and other federal bodies had put in place requirements for experimental subjects to be informed as to the nature of any care they might be receiving and the risks that any research element of that care might pose.<sup>27</sup>

Beecher's article had an even greater impact than the Salgo case. Once let out, the genie of informed consent could not be contained within the bottle of research. Nowhere was this clearer than in the treatment of breast cancer and the administration of ECT. In the case of breast cancer, for three-quarters of a century, women had undergone mutilating surgery at the hands of physicians on a mission to eradicate cancer.<sup>28</sup> In the zeal of their mission, surgeons removed ever-increasing amounts of tissue, including lymph nodes, the remaining healthy breast, and often the muscles of the chest wall. In the 1960s, women became aware that some surgeons had been questioning such practices since the 1950s, and that there was a great deal of evidence to show that less severe operations were just as successful. This was the era that gave rise to modern feminism, and the battle cry went up that male surgeons were inflicting their will on women's bodies. Women who had gained knowledge about alternative procedures and best outcomes found themselves dismissed with scorn and derision as simple housewives.

Following Salgo, the next significant case concerning informed consent involved Irma Natanson who sued her physician in 1960 for failing to inform her of the risks linked to a

new form of radiation therapy—cobalt therapy—following breast cancer surgery.<sup>29</sup> In 1955, when cobalt therapy was a new and untested procedure, Irma Natanson became one of the first women in the United States to have the treatment. Where previous negligence cases had judged physicians in the context of their peers, in ruling against the physicians in this case, the Natanson case introduced a new standard - whether the physician had “explain[ed] .. to the patient in language as simple as necessary the nature of the ailment, the probability of success or of alternatives, and perhaps the risks of unfortunate outcomes.”<sup>30</sup>

Two days after Natanson, a second legal judgment involving ECT and insulin coma, *William Mitchell v Wilse Robinson*, affirmed the same principle with even more far reaching consequences.<sup>31</sup> But before discussing with Mitchell, let us consider perhaps the most famous judgment in British medicine—the Bolam case.<sup>32</sup>

In 1954, John Hector Bolam was advised by Dr. C. Allfrey, a psychiatrist at Friern Hospital in London to have ECT. He signed a form of consent to the treatment, at a time when consent forms were not a universal feature for ECT. But he was not warned of the risk of a fracture, and during the procedure he was not treated with a muscle relaxant then widely but not universally in use. Many psychiatrists in 1954 thought that muscle relaxants, and the general anesthesia their use entailed, posed their own risks and that their use should be reserved for people where the risk of fracture was particularly great.

Should the patient—someone who was depressed—have been warned about this risk beforehand? Many eminent practitioners around London were called to testify on the case. Dr. Baker, the deputy superintendent at Banstead Hospital, said, “I have to use my judgment. Giving the full details may drive a patient away. I would not say that a practitioner fell below the proper standard of medical practice when failing to point out all the risks involved.” Dr. Page, the deputy medical officer at Three Counties Hospital, Bedfordshire, said, “Every patient has to be considered as an individual. I ask them if they know of the treatment. If they are unduly nervous, I don’t say too much. If they ask me questions, I tell them the truth. The risk is small, but a serious thing when it happens; and it would be a great mistake if they refused benefit from the treatment because of fear. In the case of a patient who is very depressed and suicidal, it is difficult to tell them of things which you know would make it worse.”

Dr. Randall of Nethern Hospital, when asked, “if you feel ... as a doctor that it is the only hope of relieving this illness, would you think it wise to discourage the patient by describing to them the possible risk of serious fractures?” answered, “I suppose one has to form some opinion whether the patient is likely to be influenced by it. Depressed patients are often deluded about their bodily health, and nothing will alter their attitude. Taking that distortion of judgment into account, it is probable that to tell a patient that a risk of fractures will not materially alter his attitude to treatment or his attitude to his illness.”

The jury decided that Dr Allfrey was not negligent in keeping silent about the fracture risk. The view was taken that the practice of not giving relaxant drugs was not unusual

for the time (although by 1957 it was very unusual.) But the bottom line was twofold. First, if a medical practitioner is behaving in a way that is consistent with, at least, a respectable minority of his peers, he or she cannot be found guilty of negligence when outcomes are adverse. Second, it was thought reasonable that if a person was depressed, the risk that he or she might misinterpret the information given was such that not all risks needed to be conveyed.

The Bolam case raised what many still think are obstacles to informed consent: what to do when a patient is irrational. This, though, is only the tip of an iceberg: If it is conceded that informed consent does not apply when the patient is irrational, where do we draw the line when patients become emotional? The case that Irma Natanson brought to the US courts seemed to belong to an almost different universe than Bolam's, and seemed irrelevant to cases like Bolam. Natanson's treatment was highly experimental; ECT was an established and widely-used procedure. Few other women in the United States had had cobalt therapy, but she was not informed of this—there was no disclosure of information. The Court was cleared while she exposed her radiation-burnt chest wall, where even the bones had been eroded to the point that her heart could be seen visibly beating. Despite this, the Court had qualms about putting the rights of the patient ahead of those of the doctors. Lawyers, after all, have to consider that what happens in one profession can happen to others, including their own, soon after.

The vast divide between the worlds represented by Bolam and Natanson was bridged by *Mitchell v. Robinson*, a Missouri case that involved shock treatments. In the United States as of 1953, practice standards for outpatient ECT had specifically advocated getting written consent from a patient's family, after attention had been drawn to the fact "that fractures sometimes occur in this treatment...., and many patients undergoing electroshock develop a temporary memory impairment." This consent, however, was aimed more at informing a family about issues to be managed rather to debate the merits of treatment.<sup>33</sup>

Against this background, William Mitchell, was treated in 1951 by an old schoolmate, Jack DeMott, a physician in a hospital run by Wilse Robinson. Mitchell was troubled by depressive disorder, alcohol abuse, and a crumbling marriage. DeMott recommended a combination of ECT and insulin coma treatments. During his seventh coma, the patient had a convulsion in which he fractured a vertebra. Mitchell filed suit in 1952, but the case didn't come to trial until 1958. He offered no testimony "to show that the insulin therapy administered to [him] failed to conform to the required standards." He did not "question the technique of administering the insulin, nor does he deny it should have been administered." "Furthermore, there is no question here as to the plaintiff's consent to the treatment or claim that the procedure extended beyond that contemplated by the consent." "The plaintiff's principal claim here is that 'There was evidence of a negligent failure to disclose to plaintiff the hazards of insulin treatment' and ... that plaintiff would not have consented to the treatment had he known of the dangers." "Thus, the serious hazards being admitted, the problem is whether in the circumstances of this record the doctors were under a duty to inform their patient of the hazards of treatment, leaving to

the patient the option of living with his illness or of taking the treatment and accepting its hazards.”

Mitchell’s case returned a verdict for the plaintiff. Although this was contested in 1960 and 1962, the implication was that in the United States, at least, the cozy world in which it was almost impossible to get a judgment against a doctor was gone forever. The standard to which doctors would be held in future was not one where their practice was deemed acceptable if some of their peers would have done things the same way, but rather a world where they had to assume that the formerly private transactions between physicians and their patients had to make sense to an increasing number of lay parties. Informed consent in this sense all but transforms patients, who endure whatever their illness or doctors inflict on them, into consumers.

### **What right does someone paid for by the public have to informed consent?**

In the case of ECT, just as in the case of breast cancer, these issues played out most clearly in Massachusetts. Fred Frankel was born and educated in South Africa.<sup>34</sup> In 1952 he spent a trainee year at Massachusetts General Hospital with Stanley Cobb, who had once been a pathologist and who was appointed to supervise the creation of a research department. Following that Frankel returned to South Africa to a clinical practice in psychiatry very much in the British style—an eclectic mix of patient support, practically oriented therapy, drug treatment, and ECT. His close contemporary in South Africa was Isaac Marks, the later founder of behavior therapy, psychiatry’s most pragmatic treatment.

When in 1962 the political difficulties between ethnic groups in South Africa exploded in Sharpeville, Frankel and his family left the country. Massachusetts General was happy to have him back. But Boston and Mass General looked somewhat different after ten years’ experience in clinical psychiatry. Cobb had been replaced by Eric Lindemann, who was one of the most famous analysts in the United States and one of the founders of the community mental health movement. Nobody at Mass General under Lindemann gave ECT. Most of the other teaching hospitals affiliated with Harvard no longer administered ECT either. This was a world in which psychoanalysis had taken over completely. Even patients with schizophrenia were treated with therapy by some of the most famous analysts in the United States such as Elvin Semrad<sup>35</sup>.

But while Harvard kept its analytic hands clean, private hospitals such as Bournewood, Glenside, Charles River, and Baldpate gave ECT to up to sixty percent of the patients referred to them<sup>36</sup>. Patients referred for schizophrenia, anxiety, substance and alcohol abuse, or personality disorders were all likely to receive ECT. In Boston, therefore, the treatment you got depended on whose door you knocked on. The split was complete, with neither side talking to each other, sharing forums, publishing in the same journals, or presenting at the same meetings. The state hospitals caught in the middle frequently complied with the new Harvard norms out of fear. By the end of the 1960s in Boston, the climate was comparable to the one that existed in North California a few years later, which led to a ban on ECT.

Frankel was struck at how ideological things were in contrast to Britain or South Africa. Something about the American psyche, as he saw it, pushed for closure on issues and the sense of certainty that went with closure. There was an intolerance of ambiguity<sup>37</sup>. The only time American psychiatry seemed to be at the midpoint was as the pendulum was swinging past it from one side to the other.

Few alarm bells rang in 1967 when Utah became the first state to pass a statute controlling the use of ECT. But they rang in earnest in 1971 when restrictions were placed on ECT in Alabama<sup>38</sup>. In *Ricky Wyatt v Dr Stonewall B Stickney*, Commissioner of Mental Health for Alabama, Judge Johnson placed a series of restrictions on treatment with ECT, which Alabama state hospitals were still giving in unmodified form. These limits were regarded by many psychiatrists as effectively outlawing ECT. The Johnson judgment is probably better understood as having been aimed at improving appalling conditions within the state hospital system. Because patients were unlikely to get the kind of clinical care they needed before and after ECT, the treatment itself could not be considered a therapeutic option. Johnson's certification and reporting restrictions on ECT forced the state to put in place many treatment provisions that had previously been lacking. As Johnson put it, anticipating the later credo of the psychiatric consumer movement, if not the survivor movement: "To deprive any citizen of his or her liberty upon the altruistic theory that confinement is for humane and therapeutic reasons and then fail to provide adequate treatment violates the very fundamentals of due process."<sup>39</sup>

In response to these developments, in 1971 Milton Greenblatt, the Commissioner for Mental Health in the State of Massachusetts, approached Frankel. Both were aware that within the Massachusetts Psychiatric Society and in the Massachusetts legislature, there was a strong push to outlaw ECT, just as there was to be shortly afterwards in California. Greenblatt decided to step in preemptively, where the commissioners in other states did not. He organized a task force to report on the use of ECT in Massachusetts, to be chaired by Frankel. While not averse to ECT, Frankel at this stage was primarily a psychotherapist. Against the advice of many colleagues who felt that this would be detrimental to his career, Frankel accepted the post.

There were a series of questions that needed to be addressed, such as whether ECT was appropriately given to patients with schizophrenia, whether it should be combined with psychotropic drugs, whether it caused memory problems or even brain damage, whether it should be given to children, and more to the point, what techniques and apparatus should be used to deliver ECT.

As a psychiatrist who had given ECT, Frankel supplied the standard advice that memory difficulties may be present following ECT but that they, in general, improved over subsequent weeks and months. He, like others, had had the experience of giving ECT to the conductors of orchestras, to academics, to business people, and to others who came from work on an outpatient basis for ECT, returning to work soon after. While this was received wisdom, no one knew for certain—through carefully designed and executed

randomized, controlled studies—whether some patients might not be affected more profoundly than others.

A potential divide here was emblematic of the times. Psychiatrists saw the dramatic improvements in cognitive function in patients who might one day be sitting mute and stuporous in a chair and the following day were doing crossword puzzles. There seemed little doubt that ECT produced benefits, indeed cognitive benefits. Patients at home, however, months later, conceivably might suffer subtle deficits of memory function, for example, about which only they could provide leads.

Also controversial was ECT for children. As Greenblatt later said, one of the issues had been a plea from child psychiatrists who “were having confused or disorientated youngsters dumped on them following multiple shocks.”<sup>40</sup> ECT for children as young as 3 or 4 had been pioneered by Laretta Bender in New York. In her view, children might experience various symptoms characteristic of the prodromes of schizophrenia, and just as children now will be put on methylphenidate or other stimulant drugs in a manner that may well appear extraordinary in decades to come, children then were treated enthusiastically with ECT by some practitioners.

A questionnaire was devised and sent out to 650 psychiatrists in Massachusetts to map ECT usage in the state. Sixty-six responded. Frankel drew up a committee to analyze the data and help him address the issues.<sup>41</sup> Shortly after the task force convened for the first time, Senator Thomas Eagleton, who had been picked as George McGovern’s running mate in his 1972 presidential bid, was reported as having received ECT on two occasions (see chapter 7). Eagleton was forced to stand down as vice presidential nominee. Who knew what it might mean to have a man with his finger on the button who had previously had ECT.<sup>42</sup> With Eagleton’s rise and subsequent fall, ECT was in the spotlight as never before.

In the introduction to the subsequent task force report, Frankel indicated that the study had come about because of civil rights pressures in general, the uncertainty about the appropriate use of ECT, and the possible effects of the treatment on memory.<sup>43</sup> The problem for the task force, as for later task forces, was to reconcile differences of opinion in the absence of evidence—because for most of the issues there simply was no evidence.

Ultimately, the logic of the data in Massachusetts, where some hospitals were giving ECT over a hundred times a year to some patients and others were simply not giving ECT at all, forced the committee back to a set of first principles. The key principle was diagnosis: It should drive treatment. They achieved consensus that a diagnosis of severe or psychotic depression might reasonably lead to ECT, even at Massachusetts General, while a diagnosis of substance misuse or depressive symptoms in the context of another diagnosis or trauma should not lead to ECT, as they believed was happening frequently in the private hospital system. This was a principle on which all of the task force members could unite, although they disagreed on the question of ECT for schizophrenia, for instance. Following this principle, they reasoned that ECT should be rarely, if ever, used for children.<sup>44</sup>

The second principle that Frankel introduced was that of informed consent. On this matter, replies to his questionnaire stated frankly that “Somebody getting paid for by the public, what right do they have to informed consent?”. Informed consent was an issue for Frankel, as he had sat on the committee set up by Henry Beecher in 1966 that attempted to drag informed consent into research, but for many psychiatrists this was the first they had heard of the concept. Few, if any, realized what a strange world they worked in. None seemed to appreciate that psychiatry allowed the committal and detention of patients, while simultaneously depriving them of the kind of rights to which anyone who was criminally committed was entitled. Detention in a mental hospital involved a more comprehensive loss of liberty than committal in the penal system, despite the fact that patients being treated had committed no crime.

Even in the 1960s, psychiatric care involved patients being told what to do. They took their Thorazine and tranquilizers when told to do so. Even in the 1970s there was no ethical debate about the wisdom of introducing long-acting depot antipsychotics to enforce compliance. It was to be another decade before patients won the “right” to refuse antipsychotics<sup>45</sup>. Earlier, patients had typically been sent for lobotomies without being consulted, and they had ECT, perhaps after being informed, but not with an option to refuse.

Following the publication of Frankel’s report in 1973, Massachusetts became the first state to issue a set of administrative regulations (as opposed to laws) on ECT. Hospitals within the state were required to report the number of ECT allocations monthly, to strictly follow consent procedures, and to limit the number of treatments a patient could receive each year to 35 or less. The rules resulted in a 50 percent reduction in the number of patients receiving ECT and an increase in the average age of those receiving it. By 1983, 26 out of the 50 states had passed statutes regarding ECT, and regulations of the sort adopted in Massachusetts had been established in six others.

But the key developments happened in California. In the late 1960s, consent requirements were tightened in the state, and were later reigned in even more<sup>46</sup>. In April 1974, John Vasconcellos introduced a bill, coded AB 4481, imposing a further set of regulations on ECT as part of the Lanterman-Petris-Short Act.<sup>47</sup> This statute required that ECT could only be given after “a) the patient gives written informed consent; b) the patient has the capacity to consent; c) a relative .. has been given a thorough oral explanation; d)... all other treatments have been exhausted and the treatment is critically needed; e) there has been a review by three appointed physicians who agree with the treating physician that the patient has the capacity to consent.”<sup>48</sup> AB 4481 was signed into law by Governor Ronald Reagan on September 24, 1974.

Meanwhile from April through December of 1974, NAPA focused media attention on the Langley Porter Neuropsychiatric Institute, a medical center within the University of California, San Francisco. This involved picket line demonstrations, public calls on staff there to engage in debates on ECT, and marches to both Langley Porter and the offices of noted ECT therapists, culminating in a San Francisco Mental Health Advisory Board

meeting in January 1975. The key point made by NAPA at this hearing concerned the lack of controlled clinical trial data in support of either the efficacy or safety of ECT.<sup>49</sup>

The constitutionality of AB 4481 was challenged by psychiatrist Gary Aden, and on December 31, 1974, one day before it was due to go into effect, it was suspended. Subsequent action resulted in a modified law AB 1032 which came into effect in 1976, but the original spirit of the law remained, and the effect was to severely limit the use of ECT in California. ECT stopped completely in San Francisco. The precedent and the publicity that went with it had a worldwide impact.

### **Damn it, I hate it when they don't breathe**

John Pippard was a psychotherapist working within the British National Health Service for his entire career. His medical career began in the Army in World War Two where he saw ECT delivered for the first time to a young soldier brought into hospital. The lad lay on the floor with electrodes applied to his head, and when the current button was pressed his body arched in a full convulsion. For Pippard the experience was both extraordinary and dispiriting.<sup>50</sup>

On returning from the War, along with many other soldier-physicians in both the American and the British Armies, he turned to psychiatry. While most people assume medical care is about treating heart attacks and tumors, military service for Pippard and others opened another window to illness, diagnosis, and treatment. They witnessed a pattern unfolding among many of the soldiers, who denied their illness when granted a leave, but complained adamantly of symptoms with little physical basis when there was no prospect of leave or discharge. In this system, the doctor was a passport to freedom, but one that first needed to be fooled, whether consciously or not. Physicians coming back from the War noticed exactly the same vague and inconsistent symptoms in many of the patients presenting to them and they began to think in terms of psychosomatic illness. This led many of these physicians to psychiatry, even though the psychiatry of the day was essentially asylum-based.

Although initially repelled by ECT, Pippard came to understand that ECT delivered results where nothing else could. After the war, he learned to administer shock treatment from scratch. When the first report of curare to modify shock treatments came through, along with colleagues, he “experimented” with the new approach. Modification made a difference, but it was clear it needed to come with anesthesia. So Pippard and his colleagues began to give anesthesia – on their own without anesthetists.

So Pippard was by no means hostile to physical treatments, but his experience in the war had led to an appreciation of how psychological factors can color presentations and responses to treatment, even physical treatments. For most of his career, Pippard practiced as a psychotherapist. As he neared retirement in 1979, looking for something else to do he spotted an advertisement in the *British Journal of Psychiatry* for research on the use of ECT in Britain. The interviewers from The Royal College of Psychiatrists

were astonished to find that among the junior doctors they had expected to be interested in the project was this older recently retired consultant, but Pippard's balanced reasonableness and prior experience with ECT won the day.

What Pippard found was a world in which ECT patients were wheeled into a communal room for treatment, perhaps with curtains between the beds, perhaps not. The anesthetist and a junior doctor delivering the treatment rolled their trolleys through the room, leaving a trail of subdued patients behind them and generating a number of increasingly apprehensive patients ahead of them. These patients witnessed the underbelly of ECT practice, down to anesthetists swearing "Damn it, I hate it when they don't breathe." If the patient next in line wasn't frightened at the simple prospect of ECT before coming along to treatment, this kind of scenario was almost designed to induce fear.

This is likely to have been the norm for ECT practice in Britain, America and elsewhere from the mid-1950s to mid-1980s, but what did it matter, if the treatment worked? But in such a lax environment, the treatment often didn't work, because patients were not receiving ECT as it was intended. The junior doctors, who were often primary care trainees without any formal training in ECT, were commonly called in to press the button after a night on-call. The patient responded with a twitch or a small spasm, and this was taken for a grand mal seizure. Against a background of modified ECT, which was supposed to almost abolish convulsions, the lack of EEG recording facilities on 1980s ECT machines in Britain meant that it took experience to know if the patient actually had had a fit or not. Vignettes like this indicating that patients might get better on non-existent ECT added to a sense of crisis about ECT as a treatment. Did it work or were people just deluding themselves into thinking it worked?

Pippard concluded that in forty percent of the British hospitals he visited, he would have been happy to be a patient and receive ECT; in a further thirty percent, the standards were unsatisfactory and he would only reluctantly have had ECT; in another thirty percent he would, under no account, have agreed to the treatment. He documented problems with obsolete machinery, unsuitable premises, low standards of care, local hospital protocols for ECT that bore little relationship to any science base, and physicians who followed an inner drummer even when the nursing staff clearly told them there were problems.<sup>51</sup> In addition, there was enormous variation in ECT use across the country with certain hospitals administering it frequently and other hospitals never employing it. Such variation was true even within the same unit: some consultants referred patients often while others never did.

The Pippard study highlighted the fact that ECT was the therapy with the greatest variation in all of medicine. At a time when the medical profession was heading into an era "evidence-based medicine" such disparities seemed insupportable. Either ECT worked and there should be no hospitals that were "ECT-free zones" and no psychiatrist who would never use it, or ECT didn't work and those who were using it enthusiastically needed to have their practices investigated. And to whom were they giving ECT? Was it personality disordered patients? Was it the kind of treatment-resistant depression that

manifested in young women in their late teens or early 20s, linked to possible sexual abuse? And if so, did the use of ECT in these circumstances reflect a further abuse?

Pippard's findings led to a working group, which advised on replacement of obsolete ECT equipment. The Royal College of Psychiatrists considered instituting a requirement for training and the appointment of regional advisors on ECT, but in the end decided, just as the APA in the United States had done, that standardization was not called for and that it was the responsibility of individual hospitals to look after their ECT service. Services in Britain did move towards nominating an individual consultant to have responsibility for ECT and distributing informational booklets for patients. But essentially little else happened.

Following the British lead under Pippard, the APA considered undertaking such an audit, but the feasibility of doing a comparable survey across a range of institutions, private and public, in fifty states seemed too daunting a prospect. Though no audit was ever undertaken, the informal view was that the US was likely to show even greater variation. Comparing the state of American and British psychiatry around the time of Pippard's survey revealed striking differences. A much higher proportion of British psychiatrists had a recognized qualification in psychiatry, but only five percent of them, compared with fifty percent of their American counterparts, worked mainly in private practice. However 71 percent of American psychiatrists who prescribed ECT administered it themselves, whereas in Britain, this only happened in private practice. In public hospital settings, junior doctors administered the treatment. Twenty-two percent of US psychiatrists were currently using ECT, whereas in Britain 45 percent of psychiatrists at least referred patients for ECT.<sup>52</sup>

That there was a perceived need for a comprehensive study of ECT at the national level was evident as both Sweden and Canada undertook comparable surveys. In Sweden, a questionnaire was sent to 74 Swedish hospitals with 100 percent compliance. As in Britain and America, there was a marked variation in the use of ECT from hospital to hospital and consultant to consultant; the most significant difference between Sweden and both Britain and the United States was that in Sweden, three-quarters of the ECT delivered was unilateral<sup>53</sup>.

The Canadian report arose following public controversy surrounding ECT in the province of Ontario. The committee, with one exception, favored continuing the availability of ECT on the basis that banning the treatment for those who freely elect to have it would be equivalent to denying them the opportunity for a better and more useful life. The Canadians also emphasized that informed consent was a prerequisite for treatment; where patients were incompetent to make a decision, there should be impartial procedures in place for determining whether treatment was appropriate or not. The committee encouraged the medical profession to look at the standards of practice for ECT as well as the quality of the machinery and recommended that all ECT outcomes should be reported to a national database, so that variations in practice could be monitored.<sup>54</sup>

For an organization such as the Royal College of Psychiatrists, faced with a report like Pippard's in 1980, the politics were simple. Little needed to be done. The notion that further work might audit progress had not been invented. But Pippard did more than establish the facts of ECT, he helped create the concept of audit. His was a first example of a profession establishing on the ground the facts of a particular therapy and setting standards to which practitioners should aspire. But he was also the first to follow up the results, and in so doing he helped create audit and clinical governance.

In 1991, Pippard followed up his earlier study. -. He found that his recommendation that ECT be given in a dedicated suite had been implemented. ECT was no longer being carried out on open wards. The general anesthetic and recovery equipment were also broadly speaking up to standard. But he still found that seizures were missed regularly and no clinic had an EEG facility linked to their ECT machine. Most ECT was still delivered by junior doctors who had no training. He maintained reservations about having ECT in half of the clinics that he audited because the machinery could not be depended upon to deliver a convulsion reliably, and the medical personnel giving the treatment were untrained and had no idea what to do should things go wrong. Where his first report had been cautiously phrased, the second, which was now explicitly an audit, was far more scathing about the failure of practitioners to recognize problems and to institute change.<sup>55</sup> This was not a case of ECT failing the profession, as he saw it, but rather of the profession failing ECT.

Over the period from his first audit, the use of ECT had dropped by a third in Britain. However there were still huge variations, with some regions having more than halved the ECT they delivered, while others increased the number of treatments. Overall there was a twelve-fold variation between the two regions that he looked at. In greater London, for example, some units used ECT so infrequently that administrative difficulties in getting it done meant that the therapy had been almost completely abandoned by the late 1980s.

A third audit in 1996 showed some improvements.<sup>56</sup> Private ECT suites were more common, and the practice of wheeling an ECT machine from one patient to the next had stopped. Most old ECT machines had been replaced and a slightly higher proportion of senior psychiatrists were involved in clinics. But for the most part ECT was still being given by untrained junior doctors in the absence of any consultant staff.

### **Memory wars**

As we have seen, from early on complaints about memory problems following ECT had been common. While recognition of these problems had long been present, concerns about memory became widespread only during the 1960s. In response, clinicians attributed such problems to the lack of oxygenation that happened in the course of the fit. Anesthetic cover and oxygenation became more common, and concerns over memory deficit were alleviated; patients no longer turned blue in the course of treatment.

With the advancement of Jan-Otto Ottosson's theory that the seizure itself was the therapeutic agent in ECT, clinicians suggested that excess electrical current was responsible for memory problems. This led during the 1970s and 1980s to a widespread replacement of the sine wave machine with an apparatus capable of delivering brief pulses of treatment (see chapter 6). In the late 1980s, under the influence of Harold Sackeim, a professor of psychiatry at Columbia Psychiatric Institute, it became the norm to limit doses of electricity to doses only marginally in excess of the seizure threshold (see chapter 10). With these developments, the clinical script changed and memory problems attributed to ECT were ascribed to the use of old-fashioned machinery delivering excess dosages.

Still other clinicians argued that the illness, depression, was the source of the memory problems. Depression itself is undoubtedly linked to some memory and concentration problems,<sup>57</sup> but recovered patients found themselves being told by therapists and experts that any lingering memory-related difficulties must be due to depression itself expressed in some latent fashion.

There is a huge range of issues at play here. Foremost is a patient's concerns about the nature of the material that has been lost. For individuals whose jobs require memory skills and who prior to ECT relied on extensively learned and utilized mnemonic retrieval systems, sometimes found that after treatment these systems didn't work as reliably and often had to be relearned. Of greater concern to patients, however, was the loss of personal, biographical memories. For example, Diana Rose, the lead author in the SURE Review of Consumers Perspectives on Electroconvulsive Therapy<sup>58</sup>, reported taking a vacation with her husband to a place of great significance to both of them, a place they'd gone before, and discovering that she had no memory of things that he told her they'd done there previously.

One of the most vivid descriptions of the phenomenon was given by Anne Donahue from Vermont, later a Representative for the State, in 2000.<sup>59</sup> Donohue's described how she was given 33 treatments in the Fall of 1995 and Spring of 1996 which she credits with saving her life, but how as the weeks went by after treatment, she found ever more areas of her life affected by memory loss. She had complete recollection in some areas of her life, total loss in others, and suspected she had created memories through external information planting in yet other areas. She reported enduring memory loss for events as significant as hosting Mother Theresa for a day in 1989, and sitting beside Colin Powell while they both received the National Jefferson Award in 1990, and the loss of events like this led her to lament the "aura of dishonesty" about this side effect. This article came 25 years after the memory was kicked off.

On September 9, 1974, the *New Yorker* magazine featured a piece entitled "As Empty as Eve" by Berton Roueché<sup>60</sup>. This covered the case of Marilyn Rice, under the pseudonym, Natalie Parker, a 44-year-old economist in the United States Department of Commerce who, in June 1972, had been referred to an orthodontist to get her front teeth straightened. Her treatment went wrong and she became depressed. She was prescribed an antidepressant, which didn't suit her, and she was then hospitalized. She was keen to

have psychotherapy, but when ECT was raised, she refused it and dismissed her doctor, John Nardini (an electrotherapist at NIMH). Her new doctor, a man named Peter Mendelis, when learning that she was the financial supporter of her artist-husband, argued that psychotherapy, being a long-term and expensive option, was not the appropriate treatment for her and that ECT would be a better bet, and she was referred back to Dr Nardini for the therapy. She was told there might be a temporary loss of memory, but that, except for the period just prior to and immediately after the shocks were delivered, it would return fully in about three weeks. As she recounts her story, the memories did return but it was her memories of things that she did not want to remember that returned first. In July 1973 she went back to work and it was then she became aware of the real problems with her memory. “I could feel. I felt as if I could think. But the fuel of thinking wasn’t there. And it didn’t come back.”

By September she submitted a disability application. In February 1974, she filed a malpractice complaint against the treating psychiatrist.<sup>61</sup> In answer to questions related to the case, Rice stated, “I have lost the vast edifice of specialized knowledge that I had been adding to almost every day of my adult life. I’ve lost the pride and self-confidence, and income that go with being an expert in one’s field. I’ve lost the intellectual joy of utilizing my mental capital. I’ve lost my value to society in that the work in which I was engaged was dependent on my unique assemblage of knowledge. I’ve lost much of my general education. I’ve lost personal memories that I would never willingly have given up—people I have met, places I have been, books I have read, plays I have seen.”

She was asked, “What was your area?” And replied, “Mine was to pull everybody else’s together . . . in the twenty some years I had been there I had worked on a number of areas . . . I had the broadest knowledge. Any one person working on a particular thing knew more about that thing than I did, but I knew the connections between the work of the various individuals.” “I had worked on the federal government, personal income, consumer expenditures, savings and investments, input, output analysis . . . I was working on an investigation of the structure of the security industry and how we used statistics concerning security transactions in our estimates of corporate profits.” “Nobody [is working in my position now]. This is not nice for my office. One of the chiefs, when I was telling him the situation in the summer said ‘but you’re the only one who has the knowledge and the patience’ and I said ‘what I am trying to tell you is, where I had that knowledge I have just a great big blank.’”

After a twelve-day trial in January 1977, a Washington jury decided Rice’s suit in favor of John Nardini. Rice went on to found the Committee on Truth in Psychiatry (CTIP), whose mission was to campaign for proper informed consent regarding ECT. Following Rice’s death in 1992, Linda Andre became the most active force in CTIP.<sup>62</sup> Andre had been given ECT in her twenties and claimed that her cognitive function had been severely compromised as a result.

An unbroken series of verdicts against patients and in favor of the treating doctor followed for the next 25 years. In 2005, *Salter v Palmetto Health Alliance et al* hit the headlines<sup>63</sup>. Peggy Salter, a former nurse, was successfully treated for depression with

ECT, but was maintained on a further course of daily treatments delivered on an outpatient basis. Memory difficulties plagued her and she took legal action. The resulting verdict in her favor was hailed by critics as a first-ever verdict against ECT. This verdict was extraordinary in a number of respects. It was returned against her referring doctor rather than the doctors who administered ECT, and it appears to have been primarily motivated by jury concerns that a woman as actively suicidal as Salter should not have been receiving daily ECT on an outpatient basis. For many Americans in the early years of the twenty-first century, managed care systems made it effectively impossible to hospitalize patients like Salter for treatment.

Rice, Andre, and Salter had engaged Peter Breggin, a former student of Thomas Szasz, as a psychiatric expert in their cases. Based on his involvement in Rice's case, and as an invited critic of ECT to the APA Task Force, Breggin wrote a book on the brain-disabling effects of ECT,<sup>64</sup> which articulated the emerging battleground. ECT caused brain damage, not just as a side effect, but as its core mode of action. If patients were properly informed of this, its use in clinical psychiatry would come to an end. To be sure, Breggin loudly and widely took this message to the streets.

### **From fear to damage**

The mechanism of ECT's therapeutic effect is still not fully understood. But the first theories of what happened in ECT were psychoanalytic. These focused on the convulsion, and the mental confusion and amnesia following ECT as a manifestation of the repressive process;<sup>65</sup> as such ECT was almost antithetical to psychoanalysis<sup>66</sup> (see chapter 5). But some psychoanalysts were prepared to see the tonic-clonic movements of a convulsion as expression of in utero movements, indicating a literal regression to the fetal level of functioning. Some even could see in the gasping of breath, in the sucking movements, or in occasional fecal smearing following ECT, the stages of Freudian psychosexual development and posited that Oedipal conflicts had been re-activated. Against this background the real therapeutic agent was the quality of the relationship the patient had with his or her therapist or primary caregiver.<sup>67</sup> ECT was the mother, in the sense of an agent of rebirth as another theory put it.<sup>68</sup>

Behaviorism, a school of thought in psychology advanced by John B. Watson, B.F. Skinner, and others, had its own theories about ECT.<sup>69</sup> Noting the level of fear that treatment could induce in patients, they argued that this was the effective therapeutic agent.<sup>70</sup> This may well have looked like the case when metrazol was used to induce convulsions rather than ECT. However, deliberate attempts to induce fear without convulsions or to verify that the element of fear corresponded to the degree of improvement afterwards proved negative.<sup>71</sup> An analytic variation on the fear hypothesis was that ECT was seen as a punishment, which when undergone allowed atonement and delivery from evil.<sup>72</sup>

Behaviorists also recognized that electroconvulsive shock (ECS) delivered to animals was a new tool with which to explore behavior through their stimulus-response

paradigm.<sup>73</sup> This research generated an interest in learning and memory, and theories based on fear were put aside.<sup>74</sup> The expectation was that memory loss was greatest for the period immediately prior to ECT; extrapolating to humans, the memories most likely to be forgotten arose in periods of greatest psychosis. One possibility was that patients actually learned a protective amnesia, as opposed to having amnesia directly caused by the treatment.<sup>75</sup> Taking this notion one step further led to the idea of using ECT for de-patterning or what was later termed regressive ECT.<sup>76</sup> (See chapter 6.) This involved giving ECT at a rate of one treatment per day or several treatments per day until the patient became totally amnesic, confused, and even doubly incontinent. As they recovered, new and more appropriate patterns of behavior could be instituted.

Another concept postulated by the behaviorist school was the competing response theory. According to this theory, the coma following the seizure produces a protective inhibition and this becomes conditioned to surrounding stimuli. If this theory is correct, ECS given at the same location as the original learning took place shouldn't disrupt learning as much as treatment given in dissimilar situations. Learning here is assumed to involve a neural consolidation process in which the formation of new memories occurs through the conversion of temporary memory traces into a more permanent form. ECS appeared to interrupt this process, leading to a retroactive or retrograde amnesia.<sup>77</sup> But efforts to test this out in animals have thrown up surprises. ECS, it appears, can lead to a proactive effect: material learned after treatment is stored better than would ordinarily be the case.<sup>78</sup>

In 1954, Joseph Brady, a leading behavioral psychologist, showed that material that had been learned before ECT, and which was apparently lost following the treatment, could sometimes be recovered. This finding caused problems not just for any theories about ECT but for theories of memory in general at that time.<sup>79</sup>

A completely different set of proposals about the mechanism of ECT became the focus of controversy in the 1970s and 1980s. In the 1950s, Max Fink and others outlined a series of organic changes following ECT. Fink's theory of the mechanism of action of ECT was a neurophysiologic-adaptive view that stemmed from studies of the interaction of brain function, personality research, and the use of barbiturates in patients with cerebral damage put forward by Edward Weinstein and Robert Kahn.<sup>80</sup> After ECT, there was evidence that EEG slow-wave activity increases with each seizure, and these EEG changes persist during the inter-seizure periods. This is a signature for an organic change state: patterns of neural activity have been altered as a result of convulsion. One way to interpret this is that the brain has been traumatized, but this view is not necessarily correct. The intriguing thing about the EEG response for Fink was that the effect could be inhibited by anticholinergic drugs, such as scopolamine or procyclidine, and enhanced by barbiturates. Anticholinergic drugs block the action of the neurochemical, acetylcholine, are not thought to cause brain damage or to reverse brain damage. Similarly barbiturates, which act as central nervous system depressants, do not aggravate or ameliorate brain damage.

What Fink described were some of first efforts to map the effects of both psychotropic drugs and ECT on the electroencephalograph, which is a quantitative surface recording of overall patterns of brain activity.<sup>81</sup> All physical treatments, including the antipsychotics

and antidepressants, turn out to have an EEG signature, or as it might otherwise be put, a distinctive set of organic changes. The organic effects of antidepressants on the EEG can, in fact, be demonstrated several months after the last intake of drug. But as EEGs have been replaced by brain scanning techniques, there has been an almost complete loss of awareness of this. Brain scans do not reveal the effect, and thus ignore an important measure of overall electrical activity apparent across the surface of the brain.

There is a world of rhetorical difference between ECT induced organic changes and ECT induced brain damage, but these early findings showing organic changes in patients after ECT were later in the 1980s put forward as evidence of brain damage.<sup>82</sup> Another feature of both organic changes and brain damage can be denial of illness. In the hands of ECT critics in the 1980s, the fact that patients might deny the existence or extent of their problems became, in its own right, an indicator of brain damage in the person treated. The bottom line was that consent to treatment could never be informed. Breggin's 1979 book on ECT introduced the claim that it was a brain disabling treatment comparable to the effects of lobotomy, which is self-evidently brain damaging, referring to ECT as electro-lobotomy. He and other critics argued that authorities on ECT, such as Lothar Kalinowsky and later Max Fink, quite openly and frankly conceded the damage caused by ECT in a more innocent time, the 1950s, but following the criticism of ECT in the 1970s, these same authorities became more guarded in their language. This new guardedness was portrayed as evidence on that the advocates of ECT and professional organizations such as APA were conspiring to defend the treatment against its critics.

Strictly following the brain-disabling hypothesis would mean eliminating not only ECT but also antidepressants, tranquilizers, and antipsychotics, for each of these agents caused changes in the brain. While many critics of psychiatry would readily sign up to throw out the pharmaceuticals along with ECT, that position, taken one step further but with the same logic, would mean that alcohol, tea and coffee should be restricted as well. In their more pragmatic moments, most people who think that brain disabling does not sound like a good idea, when presented in the abstract, concede that they readily seek disablement at moments of crisis. Indeed, ironically a good case can be made that the entire consciousness-altering movement of the 1960s, which did so much to fuel antipsychiatry, explicitly aimed at brain disablement, whether for oblivion or enlightenment. However, the idea that we should be in the business of providing humanistic rather than brain disabling treatments is a powerful rhetorical position to take, and one that retains power even when the inconsistencies are pointed out.

Compared with ECT, where no neurological sequelae to treatment can be demonstrated, antipsychotic treatment can readily be shown to produce neurological syndromes such as Parkinsonism, dystonias, or dyskinesias, and patients not infrequently develop permanent neurological syndromes such as tardive dyskinesia. Indeed brain scan research shows that one dose of an antipsychotic can alter the brain forever. It is almost certainly the case that the SSRI group of drugs, for example, can inhibit growth in children, reduce bone density, cause bleeding into the gut, womb, skin, and brain. This risk is greatly increased when the SSRIs are combined with commonly used drugs such as aspirin or other anti-inflammatory agents. There is evidence that both SSRIs, and probably antipsychotics

also, can cause testicular shrinkage, which in the case of pubertal boys is clearly not inconsequential. Compared with ECT these drugs act on all bodily systems and leave a trail of significant and permanent organic changes behind them.

But a major difference between Prozac and Zoloft compared to ECT is that Prozac and Zoloft come with the stamp of familiarity while ECT for most people is quite alien. ECT is treated as a stranger, whereas Prozac is treated as a neighbor. A critique of brain disablement works well, when the treatment is not one that the public is familiar with, but would have much less impact if it was centered on a treatment like Prozac that people feel comfortable with. There are hazards to Prozac, but rightly or wrongly, we feel we can get these into perspective and thus, continue to support its widespread use.

This point goes directly to the question of consent. Early studies on informed consent by Louis Lasagna demonstrated that volunteers to a trial of a new drug, when presented with a list of side effects, would frequently decide to withhold consent. But when later informed that these were the side effects of aspirin, their willingness to take aspirin remained unchanged.<sup>83</sup>

A further angle on the conspiracy theories, and one reason to write history, is that meanings change. It is simply not possible now, for instance, for most people to read works of early nineteenth-century psychiatrists and understand them the way they were written: a word like 'neurosis' has changed its meaning completely so that it now means quite the opposite of what it once meant. Typically clinicians and others coming into the field reading old literature, and perhaps not sympathetic to the points being made, fail to appreciate that the material they are reading cannot be taken at face value.

In much the same way, the early use of the antipsychotic group of drugs, such as chlorpromazine, was accompanied by statements by its proponents that it was offering in effect a chemical lobotomy. These efforts to describe the drug's effects were made by clinicians not operating in contested situations. They were comfortable with the idea that medicine often involves a trade-off between effects that may counterbalance (rather than cure) the changes brought about by an underlying illness. This was a generation of clinicians, who gave malaria to cure neurosyphilis, who collapsed a lung to control tuberculosis, or removed most of a stomach in order to treat ulcers. For this generation, trade-offs of this sort were the medical norm. There was no pressure to believe that antipsychotics represented a true cure for the disorders for which they were being used, only that they improve a patient's quality of life to a degree. The pressure to provide cures without consequences emerged in the 1970s and 80s, and was arguably less rational and more mythical than the earlier view of what these drugs did.

What occurred was a shift in thinking comparable to others in the course of history. In the West, cultivated gardens were once viewed as the pinnacle of natural beauty and wilderness was seen as ugly and something to be tamed. With a change in our collective consciousness, prompted by Romanticism, we now see wilderness in all its wildness as beautiful. Similarly we have also seen a cultural shift in medicine as the heroic effort to fight the scourge of disease to a view that is more likely to emphasize the wisdom of the

body and to extol efforts to work with the body. A more Romantic view of medicine, perhaps, and while this approach has its place, it can stand in the way of practical thinking about devastating illness. Romance is fine for Spring breezes, but not so good for hurricanes.

Ironically, one of the best symbols of the shifting terrain lies in *One Flew over the Cuckoo's Nest*, the book that later caused ECT so many problems. Kesey's idea for the book came from his work as a night orderly at a VA hospital, but the inspiration came from the world of diverse mental states he encountered in Leo Hollister's experiments with psychedelic drugs.<sup>84</sup> Kesey seems to have viewed ECT as not dissimilar to LSD – another means to alter consciousness. In a way that will seem scarcely credible to an ECT survivor or to those whose views of ECT have been shaped by *One Flew over the Cuckoo's Nest*, before writing the ECT scenes in the book, Kesey had a friend rig up an electrical apparatus at home, aimed at delivering a convulsion to explore what was involved.<sup>85</sup>

### **But why memory**

This is a history, not a chapter in a task force report, and hence it is not our goal to establish whether ECT causes memory problems beyond the relatively short-term problems that everyone agrees can arise for some people immediately after treatment. But memory losses following treatment emerged as a concern thirty years after ECT had been introduced in medicine. It became one of the central battlegrounds in psychiatry, and an important question for us is to consider why this was the case.

The first point is that the problems that may exist with ECT have been tremendously difficult to bring into focus. Harold Sackeim, after twenty years of research with more research funding than anyone else to look at this issue, and the resources of Columbia's Psychiatric Institute to support him, has effectively been reduced to saying: many of us think there are problems, but I cannot be more specific than this.<sup>86</sup>

The difficulties in assessment stem from many sources. Given the severity of the problems that lead people to ECT, it is likely that they will have been prescribed pharmacological treatment, such as the benzodiazepines, in the course of their clinical encounters. Drugs are routinely given in conjunction with ECT, and during ECT itself, anesthesia is used.

One of the best established facts in the domain of biological treatments and memory concerns the impact of the benzodiazepines (such as Valium) and barbiturates on anterograde amnesia—that is for memories of events that occur to individuals forward from the time treatment ensues. Classic examples involve people who have taken a pill, perhaps to alleviate the anxiety of air travel, who on arriving in at their destination will meet familiar people and then the following day have no recollection of the meeting. This is a phenomenon comparable to alcoholic blackouts. If people have been on benzodiazepines for weeks or months prior to ECT, there is every chance that memories during this entire period will not have been converted for long-term storage. Some individuals are particularly sensitive to these effects and suffer losses of memory for

highly significant personal events on what are relatively small amounts of benzodiazepine.

Almost any investigation of patients receiving anesthesia for surgery will uncover evidence of memory problems linked to the anesthesia. It is not uncommon for patients to report memory problems after ECT, but when probed, such problems are little to no different from the memory problems experienced after anesthesia for other purposes.

And there are a host of other vagaries to do with autobiographical memory which we understand very little. One of the best examples of this can be found in Timothy Garton-Ash's book *The File*, published in 1998<sup>87</sup>. Garton-Ash was a journalist working in Eastern Europe before the fall of the Berlin Wall, tracking the rise of social movements like Solidarity in Poland. In East Germany where he lived for a considerable period of time the secret police, or Stasi, kept a close watch on him. As did so many others following the fall of the Wall, Garton-Ash had the opportunity to look at his own file. A great deal of the drama in his book lay in what he discovered about himself. The Stasi had recorded, for instance, an affair that he had had with an East German woman that he'd completely forgotten about. Researching the history of ECT or psychopharmacology, it has been common to find that senior figures, when presented with programs for meetings they attended twenty, thirty, or forty years previously, may have no recollection of these meetings.

This goes to the heart of what memory is. There are great debates about whether memory involves the retrieval of almost photographic records of events laid down, in which case the inability to retrieve such events points to the destruction of some archive or the physical degradation of its contents. The alternate view is that memory is a much more constructive process and the events that we retrieve are constructions rather than videotapes of the past. A great deal of research now suggests that these constructions may be open to considerable distortion, and we may, for instance, remember abuse that never happened, as the work of Elizabeth Loftus demonstrates<sup>88</sup>. In fact it seems relatively easy to construct memories in this way, and memories of abuse, constructed or real, have been close to psychiatry's dominant theme for the past century. Memories, constructed or not, are absolutely central to psychotherapy.

The question of memory then is not simply a matter of some cognitive function that may or may not be affected by treatment. We live in a period where for various reasons memory is seen as the critical human faculty, the thing that makes us human, and it has a centrality it didn't have before. This centrality has been shaped by a variety of forces and a treatment that might degrade our memories verges on something that is considered a last resort treatment, especially for patients who expect a more psychotherapeutic approach to their disorder.

In addition to treating diseases that at the severe end of the spectrum can seem like categorical disorders, such as obsessive compulsive disorder, psychotic depression, and schizophrenia, psychiatry cannot avoid personality variations. Huge components of our personalities and our habitual modes of responding have little to do with any memories

we may have. It is unquestionably true that many individuals remain very clearly and recognizably themselves even in the face of gross memory difficulties. But these dispositional aspects to personality are not now the focus of our funded research or cultural attention, aside from the occasional debate as to whether it would be a good thing if we were all contented extraverts, managed by Prozac.<sup>89</sup> There is little emphasis on the upbringing of children aimed at managing their dispositions, as there has been in previous eras. For whatever reason, a premium has been placed on memory; this problematizes difficulties in the realm of memory to a greater extent than might have happened in other eras. The question of problems with memory that ECT exposes needs to be seen against this background.

Consider the cognitive consequences of coronary artery bypass surgery.<sup>90</sup> When open-heart surgery began during the late 1950s and early 1960s, many patients post-operatively were left clearly confused. This confusion could extend for weeks or months, and was commonly termed a post-operative psychosis (but according to post-1980s diagnostic nomenclature, this term is inappropriate).<sup>91</sup> The rate of cognitive difficulty following cardiosurgery was considerable, and greatly in excess of that linked to ECT. It was well understood by physicians and other health care staff that cognitive problems were an accepted feature of such operations, but patients were rarely informed of this. The official explanations given for these post-surgical problems parallel those given for the cognitive problems following ECT. Such patients were often labeled as being depressed and any cognitive deficits were explained as post-operative depression. However, when efforts were made to control for this by testing cognitive function and levels of depression before and after surgery, it became clear that levels of depression were greater before surgery, while the cognitive problems were quite clearly greater after surgery.

Settling the issue of depression did not prompt surgeons to accept that the surgery or anesthesia was at the root of the problem. An alternative hypothesis was that the cardiovascular difficulties that gave rise to full-blown heart disease affected the entire system including the blood vessels to the brain, leading to an incipient brain failure in addition to coronary infarction; this, according to the surgeons, was reflected in post-operative confusion. Factors such as this may have played some part, but clearly there appears to be a dynamic here where the proponents of any treatment—whether surgeons treating heart disease, psychiatrists delivering ECT, psychotherapists offering hypnosis, or pharmacologists prescribing SSRIs—are slow to see the harm they are doing or slow to accept any responsibility for that harm.

More to the point, however, is that these problems with cardiac surgery were to some extent swept beneath the carpet, even though many of those suffering will have been medical professionals with access to the means to investigate the problem. The fact that they haven't attempted to ban cardiac surgery speaks volumes about a systematic bolstering of cardiosurgery as a treatment option. The typical cardiac patient is white, middle-class, and advantaged, but for the most part those receiving ECT, at least within the United States, are of a similar profile—of European ancestry treated in private hospitals.

But research from the patient point of view on the efficacy and side effects of ECT brings to light issues that are important for all of health care. In 2003 the *Lancet* carried a review of the efficacy of ECT, which concluded that it was more effective than drug treatment for depression.<sup>92</sup> The patients' organization, Mind, objected, not so much to the findings as to the one-sidedness of the evidence reviewed.<sup>93</sup> Soon after, a review of patient views of the efficacy of ECT and the problems it might leave in its wake appeared.<sup>94</sup> This demonstrated a divide between clinician and patient perceptions. The recipients of treatment were much less likely to view it as efficacious some months later and were more aware of ongoing cognitive problems than were the physicians. Who was right?

The key question is probably not who was right, but rather should the recipients of a treatment have a place at the research table, deciding the direction and process of medical science? And if that is the question there can only be one answer. It has been clear for well over a decade that what psychiatry and medicine need is research directly involving the patient population.<sup>95</sup> Some patients experience enduring problems after ECT, but compared to post-cardiac complications, these effects are subtle. Only patient involvement is likely to sort out the resultant memory deficits after anesthetic treatment in general from those specific to ECT, and sort out whether concomitant drug intake during ECT has contributed to the problem.

But more generally, health care may be driven by arguments made by surgeons, physicians and psychiatrists for treatments that appear to them to work, where a consideration of the outcomes enjoyed or suffered by the recipients of surgical or medical enthusiasm might lead to a different set of investments. While ECT appears less effective when judged by patients, it nevertheless still appears effective; by contrast, on patient-rated quality of life scales the SSRI group of drugs, including Prozac, Paxil, and Zoloft, cannot be shown to work.<sup>96</sup> In the case of ECT research, there is no evidence that research has been suppressed, whereas in psychopharmacological research there is abundant evidence that patient ratings have simply not been published.

Good health care almost self-evidently needs good research from both perspectives. As things stand at present within psychiatry, many of the user movements set up in the 1970s have been deflected from their original mission, but they have probably not been subverted by federal funding, as they once argued, so much as been penetrated by pharmaceutical company funding. Where they have been resistant to industry funding, the companies have bypassed them and set up their own patient groups to lobby for reimbursement and media access.<sup>97</sup> When problems happen, companies can parade the representatives of their patient groups in front of FDA panels or at other hearings. This at least does not happen with ECT, whose critics remain passionate, but whose advocates are also distinguished and independent and include Deans of Ivy League Colleges<sup>98</sup>, leading surgeons who claim they would never have had a career had they not received ECT<sup>99</sup>, and even psychologists who found their preconceptions confounded by successful treatment<sup>100</sup>.



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