HISTORY OF MEDICINE

Shushaku Endo (1923–1996): his tuberculosis and his writings

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Postgrad Med J 2006;**82**:157–161. doi: 10.1136/pgmj.2005.037366

Shushaku Endo, one of the finest 20th century Japanese novelists, is not as well known in the West as some of his contemporary Japanese writers including, Yukio Mishima, Yasunari Kawabata, Kobo Abe, and Kenzaburo Oe. Mishima deals with turmoil of adolescence laced with surrealistic historical romance; Abe conjures strange, evocative images in the Kafkaesque tradition; Kawabata writes about loneliness and desolation; and Oe creates imaginary themes of life and myth that entwine and portray human predicaments. Kawabata and Oe both received Nobel Prizes in Literature. Endo's writing is different. He confronts problems pertaining to faith, morality, and individual responsibility. In his early years Endo struggled as a loner, an outsider, and a misfit. This pattern continued to a large extent into his adult life, most of which was consumed with fighting his life threatening tuberculosis. The agonies of his illness intensified his talent for exploring the complexity of human relationships.

hours playing with pebbles before returning home from school. He could see from the distance his mother's shadow as she waited to greet him. She would gently remove the flower petals from the boy's hair and jacket that had collected while he played under the trees. The first few years in the new country were happy and peaceful; the tranquility of the land was matched by the familial love and melodious music that filled the house. Gradually, and for reasons unknown to the young boy, the family environment began to change. His mother was not always at the door waiting for him; the violin music had become melancholic, and monotonous. He couldn't fathom the reason for the unsettling pall, but he could recognise furrows of sadness on his mother's face. Then came bickering and shouting between the parents. First random and brief, the arguments soon became prolonged and vicious. One day, when Shushaku was walking with his father, he was abruptly told that his mother would return to Japan. When asked if he would like to accompany his mother, the boy kept walking, silent, kicking every rock on the street. He felt abandoned and frightened. After a few months, with money from her sister, the mother with her 10 year old son moved back to Japan.

Kobe, the bustling cosmopolitan community on the Osaka Bay, became their new home. It was the hometown of her mother's family who were supportive and welcoming. Shushaku's aunt, an ardent Catholic, persuaded her sister to adopt Christianity. Soon after, on his mother's insistence, at the age of 12, Shushaku was baptised, and christened Paul. Thus, within a period of two years, two significant decisions that were to influence his writing were foisted on him by circumstances beyond his control. He neither had information nor means to desist.

Shu-chan, as his mother used to call him, was enrolled at Noda Elementary School, Kobe. The boy did not enjoy school. In those ultra-nationalistic days in wartime Japan, he had two strikes against him; his Christian faith, and his resistance to militaristic education. He was constantly harassed and mercilessly teased by children; his grades slumped. The situation did not improve when he moved to junior high school. Despite his unsatisfactory performance at the school, his mother remained loyal. She declared to family members and relatives that Shu-chan would become very famous and would do more for humanity than any other member of the family. "He who knows his mother's love and is secure in that knowledge will never know failure," wrote Freud. Endo's mother provided him that secure love and confidence.

Illness is a convent which has its rule, its austerity, its silences, and its inspiration. *The Plague* Albert Camus (1913–1960)

THE BEGINNING

Shushaku Endo was born in the Sugano district of Tokyo in 1923 to a well to do middle class family. His father, a successful salary man, worked for a bank. When the child was 3 years old the senior Endo was transferred on a business mission to Dailin (Dairen) in Manchuria, which was then under Japanese control. Although the move may have uprooted the established, comfortable city life for the family, Dailin, nevertheless provided a gracious living. With its well defined four seasons, wide acacia lined streets, and elegant European architecture, the city had earned the title of "Paris of the East". The Endos found a small but suitable residence located in the middle of a row of houses bordering a quiet street. The windows of the house permitted ample light and gentle breezes during long summer days. In the winter months, the window panes turned into a canvas of glittering fish teeth icicles. In the evenings when the sun was still in sky, the boy spent

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Submitted 16 May 2005
Accepted 7 July 2005

THE MIDDLE

At the age of 20, Endo entered Keio University, Tokyo. By now his relationship with his father was tenuous, limited to small financial help for educational expenses and to even this meagre donation, there were strings attached. The father wanted his son to become a doctor, but despite his father's demands and threats, Shushaku avoided registering for the medical school entrance examination. The obdurate father disowned his son and the rift became permanent. Many years later when Endo married Junko, his father boycotted the wedding. This chasm between the father and son had its beginning when the 5 year old boy was asked to choose between two bitter, stubborn people. He had chosen his mother as any child thus trapped might do. The cruel and searing memory determined his resolve to remain on his mother's side. It was an ironic twist of the fate that when his mother was dying, Endo, because of ill health, could not be at her side. To remain faithful to his mother's memory, later, when his father was dying, Endo refused to be at his deathbed. The revenge was calculated and complete; only after the father had passed away, did Endo enter the dead man's chamber. This reluctant gesture at the insistence of his wife, Junko, closed the sad chapter between the two men caught in tragic circumstances.

At Keio University Shushaku took up French Literature. With no financial support, he secured a part time job in an army ammunitions factory. The workplace was cold, damp, and crowded. His room in the dormitory was unhygienic and exposed to the elements. His stressful living environment and poor nutrition made him ill. He began to cough, developed fever, and started to spit blood. Barely 22 years old, Shushaku found himself in the grip of tuberculosis, then, as now, a deadly disease.

In 1950, at the age of 27, Endo joined a group of Japanese students who went to France, at government expense, to study. The ocean voyage was gruelling. After remaining closeted in a fourth class cabin for six weeks, the group arrived in Marseille. After the war, there were only a handful of Japanese in France. At the University of Lyons where Endo would study French modern literature and Catholic theology, there were only three Japanese students. In this rather alien and unwelcoming environment Endo found solace in exploring the teachings and philosophical discussions of Julien Green, Georges Bernanos, and Francois Mauriac. The latter examined the ugly realities of modern life in the light of eternity and became a strong influence on Endo's writings. Today Endo's works are often compared with those of Graham Greene and Mauriac.

As one of the first Japanese overseas exchange students in France, the young man became a butt for racial insults; even his fellow Christians joined in casting ethnic slurs. Depressed, in poor physical health, he returned to Japan after three years. He found his homeland changed; his world was filled with new uncertainties. Doubts about his health, doubts about his faith, and doubts about his future plagued him. He threw himself furiously into writing.

His first story *Aden Made (As Far As Aden)* appeared in the literary journal, *Mita Bungaku*. One year later he was awarded the Akutagawa prize for his book, *Shiroi Hito (A White Man)*, which was published in another prestigious journal, *Kindai Bungaku*. In these works he began to systematically explore the complex and contrasting relationship between East and West, faith and faithlessness, tradition and modernity. Stress, long and irregular work hours, suboptimal nutrition, and harsh environmental conditions caused reactivation of his lung disease. He coughed up blood and lost weight; fever returned and weakness increased. In the early 1950s medical treatment of tuberculosis was primitive. Streptomycin and para-aminosalicylic acid were the only two drugs available; the former had to be injected, the latter caused distressing

nausea and vomiting. In difficult cases, air was injected into the pleural cavity to collapse the diseased lung. In his semi-autobiographical novel, *Umi To Dokuyaku (The Sea and Poison)*, Endo analyses the tribulations of disease and the doctor-patient relationship. The title represents the sea as destiny that washes away human beings as tiny specks intellectually paralysed by the poison of their actions. Endo uses Dr Suguro and his profession as the canvas to paint a searing picture of man's capacity for inhumanity.¹

The story is based on an actual incident that occurred at the end of the second world war at Kyushu University. An American crew member of a B29 bomber, captured at the time of an air raid on the Japanese mainland, was subjected to vivisection. The protagonist, who suffers from tuberculosis, finds himself in a doctor's office to receive a pneumothorax.

"As I lay on the creaky bed, he held the x-ray in front of his nose, studying it with blinking eyes.

'I was getting 400 c.c. air from my last doctor.'

Dr. Suguro did not respond. I looked fixedly at him as he took the glass bottle containing the pneumothorax needle from a drawer of his desk, examined the hole at its tip, inserted it into the rubber tube, and prepared the anesthetic shot. His thick, hairy fingers moved like caterpillars. There was dirt packed under the fingernails.

'Raise your arms.' he ordered me in a low voice.

His fingers probed my side for the spot between the two rib bones. He was making sure of the place to insert the needle. There was a cold, metallic chilliness to that touch. More than that, there was an impersonal, unfeeling competency to it that seemed to deal with me not as a patient but as some sort of laboratory specimen....

'No sociability, that's all. There are a lot of doctors like that.' my wife said."

As it turns out Dr Suguro, who practises in a small town outside Tokyo in a dingy office is haunted by his own past experience. During the war he had served as an intern in a hospital where his superiors were more interested in career building than in the healing. Suguro was induced to assist in a horrifying vivisection of a prisoner of war. His colleague, Toda, says to him, "Doctors are not saints. They want to become full professors. And when they want to try new techniques, they don't limit their experiments to monkeys and dogs. Suguro, this is the world, and you ought to have a closer look at it."

'What is there to do?' He spoke in a weak voice. 'What are we going to do?'

'Nothing. Just do as we always do. Nothing has changed.'

'But today! Toda, it doesn't bother you at all?'

'Bother me? What do you mean, bother me?' Toda's tone was dry. Was it the sort of thing that should bother somebody?

Suguro was silent. Finally as though to himself, he spoke in a feebler voice. 'Toda you are strong. As for me... I shut my eyes today in there. I just don't know what to think, even now. I just don't know.'

'What is it that gets you?' Toda felt a painful constriction forming in his throat as he spoke. 'Killing that prisoner? Thanks to him, we'll now be better at curing thousands of TB patients- because we killed him. Should we have let him live, you think? The conscience of man, is that it? It seems to vary a good deal from man to man.'...

'Still...some day, we're going to have to answer for it,' said Suguro, 'That's for sure. It is certain that we're going to have to answer for it.'

'Answer for it? To society? If it's only to society, it's nothing much to get worked up about.' Toda gave another yawn. 'You and I happened to be here in this particular hospital in this particular era, and we took part in a vivisection performed on the prisoner. If those people who are going to judge us had been put in the same situation, would they have done anything different? So much for the punishment of society!'

Whatever Endo's personal faith or lack of it, he was obsessed with the power of individual freedom and responsibility, particularly responsibility to society during the time of war.²

Endo's chronic illness had given him the opportunity to study the medical profession at close quarters over a long period of time. He was disappointed in his doctors. He said that they had no training in treating the soul; they only bandaged and patched the body. Junko recalled that her husband used to say, "Doctor, priest, and novelist can put out their hands and touch the soul." He was disappointed to see that doctors failed the challenge. Endo wanted medical schools to provide an appropriate environment for the teaching of ethics, morality, and civic responsibility. It was painful for him to see doctors distorting their lives for the sake of making a livelihood.

His chronic tuberculosis and its debilitating therapy constantly interrupted Endo's learning and writing. It played havoc with his physical condition and caused a great deal of mental anguish.

In *When I Whistle*, a seemingly artless but tightly and cleverly constructed novel, Endo weaves a rich tale set in two worlds—the world of pre-war Japan, and the contemporary one in which a large hospital with its professional rivalries sometimes uses patients as pawns. As the story evolves, Ooze, a middle aged businessman, relives the past while his son, Eichi, a surgeon, pursues his ambition and materialistic machinations to unseat his rivals and get ahead at any cost. Endo is precise and demands his readers recognise the moral imperatives that govern men's lives.³

"Then...the patient is the very first test case, isn't she?"
 'I can't comment about that.'
 'You can't comment! Well, what if this patient was a relative of yours—would you still give her this test drug? What if she was your mother? Or, your sister?'
 'I probably would.' Eichi replied, after a moment of silence. 'No matter what kind of drug you're talking about, you have got to have a patient to use it on for the first time so you can improve it and judge its effectiveness.'
 'We are not like Jenner discovering vaccination. When we try out a new drug, it's either got to be because another drug is no longer effective, or when we have the patient's voluntary consent. One or the other. Do you have her consent?'
 'This is hardly the time for you to put the screws on me. In America they test out new drugs on convicts...'
 Tahara stared at Eichi in surprise. Then a look of sadness washed slowly across his eyes.
 'Do you really believe that?'"

In 1959, Endo, because of a severe hemoptysis, had to be re-hospitalised in Tokyo University Hospital. There he underwent a cycle of bronchoscopic examinations and received many more artificial pneumothoraces. Bronchoscopy, a primitive procedure in those days, was performed by using a rigid bronchoscope, a hollow, hard, and cold steel cylinder. The process was particularly brutal

because there were hardly any effective sedatives, analgesics, or cough suppressive drugs available. The instrument was plunged into the throat and pushed into the air tubes and the lungs. Gagging and suffocating, the poor patient was held on the table by half a dozen nurses and attendants. Endo called the test "The Barbecue". After every bronchoscopic examination, he would come out pale, drained, exhausted, and numb. Bleeding from his lung continued and when it was no longer possible to stop the bleeding and control the disease by repeated pneumothoraces, it became necessary to subject him to one of the most disfiguring operations in the annals of surgery, thoracoplasty.⁴

The first thoracoplasty was performed by a Swiss surgeon, De Cernville, in 1885. The procedure entails removing the ribs in stages, two or three at a time, while leaving the fibrous covering of the removed ribs in place. After the operation ribs regenerate in new positions and create a reasonably stable but deformed thoracic cage. The procedure works well for a unilateral cavitory lesion, but it remains hazardous. After the operation the survivor suffers the humiliation of looking, in Endo's words, "like a boneless fillet of fish". To avoid shock the ribs are removed piecemeal, over several operations. Bleeding and infections are common complications.

Endo had extensive multistage thoracoplasty, followed by many corrective procedures to deal with the complications of broncho-pleural fistula and infections of the pleural sac. After the final operation he looked like a "one winged airplane". Many patients who were thus treated managed to subdue their disease. Many more, however, either died during or soon after the operation, or slowly succumbed to lung and heart failure within a few months. Tuberculosis in those days lowered a huge percentage of its victims to their graves.

Considerably weakened by the disease and multiple operations, Endo, by his 39th birthday, needed prolonged rehabilitation and recuperation. Although his health was far from perfect, he remained optimistic about the future. He did not follow the road taken by many well known Japanese writers who, under stress, had committed suicide including, Kawabata, Mishima, Akutagawa, and Dazai among others. Endo told Richard Schuchert, a Jesuit preacher, "Here is a Japanese writer who is not going to commit suicide." Endo's strategy against tuberculosis was very different from the struggle of another famous Japanese writer, Mori Ogai. The latter, when developed tuberculosis elected to remain quiet and secretive and suffered in silence for fear of being ostracised from society.⁵ Mrs Endo confided to me, "After every hospital admission and after every invasive procedure, he looked forward to coming home in good health and renewed enthusiasm to write uninterrupted."

The long recuperative period gave him an opportunity to look back at the religious conversion that was forced on him in his childhood. His Christianity, he thought, was like an ill fitting suit, not consonant with his needs. He began to explore other faiths, other beliefs. The exercise, in 1964, resulted in *A Forty-Year-Old Man*, one of the most admired of Endo's stories. Not only does it confront the economic, social, psychological, and spiritual effects of a lengthy illness, but it also introduces an important literary symbol—a myna bird, a sorrowful, priestly figure that observes the hero's action with pity and without judgment or condemnation. The hero of this autobiographical tale suffers a heart stoppage and almost dies during surgery. Miraculously, he survives, but after his recovery finds out that his favourite myna bird has died. When he inquires about the bird, his wife answers, "I am sorry. But I feel as though it took your place I buried it at home in the garden." Here Endo takes an unusually bold step of injecting the concept of reincarnation and transmigration of the soul into his writings. He was interested in occultism and life after death and thought it possible that one's choices

could change another's destiny. There is a curious anecdote relayed to me by Mrs Endo. As a form of relaxation Shushaku enjoyed smoking, whether he was listening to music, reading in the afternoon, or just being with Junko, his wife, in the evening after dinner. He smoked heavily for decades and would not give it up. The addiction, however, unshackled him when his loyal maid died of lung cancer. Endo gave up smoking as a sacrifice, so that his maid's spirit might enjoy eternal peace.

The spiritualism of India attracted him; he visited the country four times. In Varanasi (Benaras), on the banks of the Ganges, Endo sat motionless, in a deep trance. The noise and liveliness that accompanied cremation rituals neither perplexed nor disturbed him. In Japan, cremation and burial are solemn affairs enveloped by a pin-drop silence punctuated only by soft murmurs of condolence and praise. Junko remembered her husband saying that the loud music and the chorus of unintelligible languages on the ghats of Varanasi were indeed quite appropriate. He understood that Varanasi invites pilgrims and families of believers from all parts of the world to take a dip in the Ganges to wash off their sins. A small number arrive to stay in the city until the end. Endo wrote, "People sometimes wonder when they will die.... But they never give much thought to where they will breathe their last." The believers who come to die in Varanasi know where they will be when they exit this world. The act guarantees their entry into heaven. The belief, so alien to the Western mind, is so fundamental to more than a billion people on this earth. In Varanasi, it is believed that the soul stops at the holy Ganges just for a moment to shed off the ugly body. The beautiful, unsullied soul then moves on to become one with the Creator. Varanasi touched a tender spot of Endo's psyche. With philosophical disinterest he strived to untangle concepts of incarnation, reincarnation, and transmigration of the soul. The holy Ganges became the background for his powerful, philosophical novel, *Deep River*.⁶

Death in Varanasi was not unlike the Negro spiritual prayer, "Deep river, Lord: I want to cross over into the campground". The spiritual longing of the Negro was parallel to the Indian belief of going to heaven after crossing the Ganges. The human need for salvation of the soul and the thread that connects two so totally different peoples captivated his imagination.

In *Deep River*, Endo brings to Varanasi a group of confused, restless, and troubled Japanese tourists. Isolated and unloved, they doubt everything and believe in nothing; their souls, saturated in sceptical materialism, drift in many directions. Endo brings them to the Ganges in the hope that they might find solace. It becomes clear that his characters find it impossible to drop the ennui they had accumulated before coming to Varanasi. The moral compass needed to lead them out of the irrational mess was not a part of their spiritual equipment. Endo watches: his characters drift back to their original stations, living in the ways they had done before coming to Varanasi. Endo showed them a collage of beliefs, a panorama of clashing cultures; he did not tell them how to achieve salvation. Individual choice would determine that. *Deep River* is a masterful and devastating criticism of the world that lacks moral substance and direction.

THE MAN

During the 41 years of his blissfully happy married life, Endo never discussed his work or his books with his wife. Curiously, he also forbade her from reading his books except *Silence*, *Deep River*, *Wonderful Fool*, and *Samurai*. He wrote every day and read two news books a day. He would get up in the morning a little before 10 am and write for three to four hours. Music was always on, particularly that of Bach, Faure, and modern French composers. Endo wrote not only serious

novels but comical essays as well. He created Korian, a humorous character that was partially autobiographical. These essays were extremely popular in Japan and reflected the slyly comic side of Endo. One of the famous Korian tales is called *Wig*. It portrays hilarious misadventures involved in the purchasing of a wig by Korian. Earlier on, Endo had been advised by his publisher to give up humorous writing because it might become detrimental to his reputation as a serious writer. Endo refused and replied that his humorous stories were for other people and his serious writing was for himself.⁷

He loved the stage and wrote for and played in musicals. An inveterate traveller, Endo was fond of England and had once considered buying a house in Sussex. He admired the sense of fair play and discipline of the British. He spoke good, if heavily accented, French and preferred to speak with Europeans in French, although he was not enamoured by what he termed the "frivolousness and artificiality" of Paris. He admired American forthrightness and democratic ideals. Despite his obvious enjoyment of other cultures, Endo remained fervently Japanese at heart. He would tell Junko, "It matters little whether I am in London, Paris or New York. Once I am in my hotel room, behind closed doors, I am in Japan."

Endo received honorary Doctorates from several universities in the United States, Taiwan, and Korea. America awarded him the Campion Prize. He was, however, most proud of Bunkakunsho, the most prestigious of the Japanese literary awards, presented to him in 1995 when he was 72 years old.

THE END

In 1994 Endo sustained a stroke. Paralysed and not able to speak, he was rushed to a hospital. He would not leave the hospital now; neither would he write again. A vision appeared to him in which he saw his mother, but not his father. On 29 September, 1996, with Junko's hand in his, Endo uttered faintly, "I am entering the Light" and peacefully moved on to the next stage of his journey.

Endo embraced the human drama in its entirety. In this respect he was distinct and different from contemporary Japanese writers. Although he wrote many books, stories, and plays, Endo condensed his experience into four books that represent acme of his literary output; *Wonderful Fool*, *Samurai*, *Silence*, and *Deep River*.⁸ The long ordeal with tuberculosis marked his writings and gave them a universal voice. He did not shy away from presenting evidence of the incurable isolation that he had faced in his life and that each of us must face despite our beliefs. Finally, we must die alone.

ACKNOWLEDGEMENTS

I am grateful to Mrs Junko Endo for her kindness and generosity of spirit in discussing Mr Shushaku Endo's life. My thanks are due to Dr Megumi Kokura who organised my interview with Mrs Endo and Drs Yutaka Hosoda and Sonoko Nagai for kindling my interest in Shushaku Endo's life.

ADDENDUM

On 13 May 2000, Endo Shushaku Memorial Hall museum opened in Sotome Town, Nagasaki Prefecture. The museum sits on a beautiful hill overlooking the East China Sea. The site was chosen by Mrs Junko Endo and the museum was designed by Jiro Hiroshima to symbolise Japan's cultural gift to the world. It contains over 7000 books and the desk and chair Endo used when writing his last novel *Deep River*.

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WEB TRAWL

This month's web trawl evaluates three UK based web sites for organisations dealing with issues relating to impaired hearing.

<http://www.rnid.org.uk> This is the web site of the Royal National Institute for Deaf People; the UK's largest charity working to assist those who are deaf or have some degree of hearing impairment. The home page provides links to a variety of resources designed for patients and their families, employers, and health professionals. As the RNID is a charity, there is a major focus on fundraising and there are links to information relating to events that patients and their families especially may wish to become involved in. For those interested in learning British sign language, details of courses are provided. For employers, a comprehensive section advises on the responsibilities they have towards hearing impaired employees and how they can go about meeting these responsibilities. The UK's Disability Discrimination Act is covered in some detail and there are factsheets relating to it that may be downloaded. The web site also has an online shop, selling products from telephones to smoke detectors, which have been designed specifically for deaf people. Although this web site is probably aimed less at health professionals, it is nevertheless worth being aware of the web site and its contents, so that it can be recommended to patients.

<http://www.hearingconcern.org.uk> Hearing Concern is another UK charity set up to help those who are deaf or hard of hearing. From the home page, the user can navigate to further pages detailing activities of the organisation, in particular, campaigns currently underway to improve the lives of those with hearing impairment. Subtitling on television, telecommunications, and the provision of audio induction loops are all covered. With regard to subtitling, Hearing Concern runs a monitoring project, and the web site published details of a "subtitling scoreboard" listing the percentages of subtitled programmes available on television in the UK. Users of the web site are encouraged to become involved with lobbying and campaigning, and to that end a link is provided to the UK parliament web site that permits the user to search for the name and contact details of their local MP. This web site again is not aimed specifically at health professionals, but it is again worth being aware of its existence, so that it can be recommended to patients.

<http://www.mhas.info> This is web site of the Modernising Hearing Aid Services, and unlike the other two sites is aimed more at the health professional, and audiologists in particular. From the home page, patients are directed via a link to the RNID web site, as detailed above. A limited number of links are provided; a page entitled Audiology Resources is accessible only to health professionals and provides data that are probably only of use to audiologists. Of more general interest is a page of links to other relevant organisations, and in fact this seems a more comprehensive list than those found on the other two sites. This web site is unlikely to be of use to many apart from audiologists, but the page of links to other web sites is probably of more general interest.

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