

# Mothering to death

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## Abstract

**Three families are described in which the healthy only child was, from early childhood, put to bed and treated as if ill, dependent, and incapable. This abnormal mothering continued for 28, 45, and 48 years, respectively, and the children died as disabled adults. In each case, the three mothers evaded medical, educational, and social services. The origins of their behaviour are examined, and the links with more common forms of separation anxiety, school refusal, and perceived and factitious illness are discussed.**

(Arch Dis Child 1999;80:359–362)

Keywords: child abuse; neglect; separation anxiety; Munchausen syndrome by proxy

Classical and romantic literature is scattered with references to spinsters who spend their lives in bed feigning illness and being pampered by those around them. The usual suggestion is that such women have suffered a midlife tragedy causing them to retire from life and go to bed.

However, a bedridden life can be imposed on children and, although the child may be intrinsically healthy, the psychological and physical consequences of being kept in bed and regarded as ill may ensure lifelong perpetuation of this lifestyle.

Three families are described in which, from early childhood, the child was encouraged to stay in bed and to be dependent on their mother's care. The children remained in bed, cared for by their mothers, until they died. In contrast to cases of factitious illness, in which mothers invent or cause illnesses for their children and present them repetitively and persistently to doctors, in these three cases, medical professionals and the health services were either not involved, or were involved to a minimal extent. The origins of this abnormal mothering are discussed, together with its relation to more common mother-child separation difficulties, and to the more usual forms of perceived and fabricated illness.

## Background

The three families were notified to me by colleagues who were aware of my interest in unusual forms of child abuse. I visited the towns where the families had lived, met surviving relatives and neighbours, and interviewed some of the health and social work professionals involved with the families. I studied the available past records and visited the local newspaper offices to seek information about the results of inquests and the way in which the three deaths had been reported. The state-

ments in quotation marks came from the interviews and reports. The patients' names are fictitious.

## Pat

Pat died at the age of 28 years. She had spent the last eight years of her life in a sofa bed, bandaged in pieces of torn sheet. Her dead body was found in a room with her pet rabbit, budgerigar, and cat in her mother's home. A week later her mother died.

Pat was the only child of healthy parents, and was born in the late 1950s. The pregnancy, although unplanned, was uneventful. She was a healthy baby, born after a normal delivery. At the age of 3 months she had mild eczema for which she was taken to the general practitioner; a cream was supplied, and the mother was advised that if Pat scratched at night she should wear mittens. From then on she slept beside her mother and continued to do so for the rest of her life, for the first 16 years in the same bed, and then on an adjacent sofa bed. The eczema waxed and waned, but was not particularly severe. Her mother clad her limbs in bandages.

The family lived in a terraced house in a medium sized town. She did not go to school. She was taught to read and write by her mother. She conversed intelligently and understood complex television programmes. She could read books. She rarely went out, and when she did so it was with her mother. Neighbours observed that her mother seemed to put Pat "in a glass case and wouldn't let her out".

By the time she was 16 years old her father occasionally took her to the restaurant where he worked; there she would sit on her own for the evening.

When she was 18 years old her father left to live in another town with a man. Pat's mother began a relationship with another man, but Pat's behaviour became extremely manipulative and she began to have what were probably pseudoseizures. The seizures stopped when her mother's relationship stopped. Thereafter, she lived at home, being looked after by her mother, and did not go out.

At first Pat was mobile and would have been able to use the toilet facilities in the adjacent room, but her mother did everything for Pat, washing her in her chair and not allowing her to walk to the bathroom. She was encouraged to use a pot by the sofa bed rather than the toilet.

For the last eight years of her life she lived on a sofa which had been converted into a bed in the downstairs room next to her mother's bed. Although her childhood eczema had gone into remission by the time she was a teenager, her mother continued to wrap her limbs and

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Accepted 20 November 1998

sometimes all her body in bandages. Pat developed severe contractures of her joints. For the last two years when she needed to go to the toilet her mother lifted her out of her sofa bed and placed a tray beneath her.

Pat's mother drew no money to support her because of her fear that if she tried to do so a medical report would be needed, and she was not willing to be involved with doctors or social services. The doctor had not been called out to see her during her life.

Social services had been contacted by a neighbour because of cries being heard from the house. A social worker gained access to the house several times and numerous appointments were made for Pat to see a doctor, but the appointments were cancelled by the mother. The health visitor had offered Pat a place in a day centre, but Pat's mother cancelled it.

When she died, at the age of 28, Pat weighed only 21 kg. At the inquest the coroner returned a verdict of "natural causes due to malnutrition, but aggravated by self-neglect", and said that her mother "loved her too deeply, but had become misguided".

The local authority said: "we all tried to help this family, but we could hardly hammer down the door and take this woman away" . . . "It is true she never went to school. The parents have to register children with us, but if they never get in touch it is possible she could slip through the net" . . . "Social services cannot force themselves on people. We can only really act if we are called in." The general practitioner commented: "it's a free world, people should be able to do as they want". Her father, who had not seen her for several years, did not consider there was any suggestion of cruelty or lack of concern from Pat's mother: "she just used to treat her like a baby".

### **Mabel**

Extract from a newspaper: "A hypochondriac spinster took to her bed as a teenager and spent the remaining 50 years of her life there, wearing make-up and eating chocolate."

Mabel was the only child of healthy parents. Her birth and early life, in the 1920s, were unexceptional. Her developmental progress was normal.

Shortly after starting school at the age of 5 she developed an infected cervical lymph gland which required drainage and antibiotic treatment. She had her tonsils and adenoids removed. After that she attended very little school. Her mother treated her as ill and put her to bed; in the eyes of her relatives and neighbours she was "pampered" and "spoilt". The parents kept her in bed "with them fussing around her", recalled one relative. She had very little formal education, spending most of her time at home "ill". Her mother said that there were a variety of different things the matter with her, although neither doctors nor hospitals were involved, and she did not appear an ill looking child to the neighbours.

Just before the start of the second world war when Mabel was 16, she had two part-time jobs; each lasted for less than three days

because she did not like them. She stayed at home where her mother looked after her—in bed. Neither relatives nor neighbours saw her out of bed thereafter. Her father died when she was 18 years old, and from then on her mother looked after her without support.

Mabel remained in bed for the next 30 years, being looked after by her mother, until her mother died of cancer. Then for a further 16 years, still in bed, she was looked after by neighbours and relatives. She lived in bed in a downstairs room of her council flat. She did not use the other rooms of the house. A neighbour prepared her meals and took them to her, and did her shopping.

Until the time of her mother's death, neither nurses nor doctors were involved. But after her mother died, general practitioners were involved with her care. She was regarded as a very difficult person and very demanding.

In the later years, social services provided a part-time home help for her and the district nursing service helped with her care. The district nurse said that Mabel periodically injured herself to gain more attention.

Terminally, Mabel became reliant upon sleeping tablets and tranquillisers, and it is probable that an excess of these contributed to her death at the age of 64. At the inquest into her death the coroner recorded a verdict of death by misadventure.

### **Malcolm**

Malcolm was born in the early 1940s. He was the only child of healthy parents and was a healthy infant. The parents separated when he was 2 years old, after which he had no contact with his father. The neighbours recall that he had seemed a normal child, who was acquiring the usual developmental skills. By the age of 3 years his mother was reporting to relatives and friends that he would not eat normal food, and that he was "poorly". His early attendance at school was scanty. By the age of 7, he was confined to bed and receiving no education.

Malcolm and his mother lived in a terraced house in a town that had the usual National Health Service medical resources. However, his mother did not use those medical services, and doctors were rarely involved.

He continued to be nursed, as if a baby, in bed or in a chair throughout his teenage years into adulthood. Few people were allowed into the house, but a neighbour recalls seeing in the corner of the back room a pale young man propped up in bed, as if incapacitated. It does not seem that his mother applied for benefits or aid to care for him.

He continued to be fed on liquids and to be nursed in bed until his mother died when he was 45. At that stage he was extremely wasted. He talked, but could not read. He was considered to be of average intelligence. He had major contractures and was confined to a bed chair, from which he could not move. His mother's death led to the intervention of social and medical services, and his transfer to long term care, where he died two years later.

### Discussion

The three cases do not fit easily into the usual categories of child abuse, although they encompass both neglect and emotional abuse. Moreover, although each was perceived, by their mother, to be ill, to require constant care, and to be unable to go to school or fend for themselves, the cases do not fit the usual pattern of Munchausen syndrome by proxy abuse. Usually when mothers invent or cause illnesses for their children they rely upon doctors and the health services as their accomplices; and it is often the medical care, in terms of investigations, surgery, and other management procedures, which does much of the direct harm to the child.<sup>1</sup>

The unusual feature of the three cases reported here is the way in which the mothers actively avoided contact with doctors, hospitals, and other agencies, suggesting that they realised that intervention from those sources might alter their way of life and their child's future.

There are some similarities with those cases of undetected Munchausen syndrome by proxy abuse, extending over many years, in which older children have come to regard themselves as ill, and to assume abnormal illness behaviour themselves as adults. Thus, there have been reports of adults regarding themselves as disabled, or confined to a wheelchair, as a result of their mother's insistence in early childhood that they were ill or disabled.<sup>2</sup> Several of those have been in families in which other children have suffered more common forms of Munchausen syndrome by proxy abuse—for example, factitious epilepsy.<sup>3</sup>

The reports from those who knew those children as adults is that each of them believed themselves to be incapacitated. Two of them became genuinely incapacitated as a result of their lives in bed and the subsequent contractures that developed. The other, Mabel, was not incapacitated physically, but she believed herself to be incapable of being out of bed and active. The way in which she became involved in self injury, and exaggeration of symptoms, suggests that after her mother died she had learnt ways of ensuring evermore involvement and attention from carers.

All three children in early life were normal, healthy, and active until their mothers put them, and kept them, in bed. The mothers themselves were considered to be normal and healthy and were not considered to be mentally ill. There is no evidence that the mothers deliberately falsified symptoms or signs or that they deliberately injured or physically abused their children. However, they did provide misleading information about the child's health to neighbours, relatives, and the schools; and most important of all to their children. Their perception that their child had a physical problem preventing normal life and schooling must have verged on a state of delusion. They deemed their children to be in need of perpetual mothering, and mothered them until they died.

The motive for the mother's behaviour was not typical of Munchausen syndrome by proxy

abuse—seeking the advantages of the sick role for themselves, or as another form of attention seeking behaviour.<sup>4</sup> Nevertheless, there must have been strong maternal needs to over-protect and care for their child, and to treat their child in an inappropriately dependent infantile way, as well as a fundamental unwillingness to allow their child to develop as an independent, resourceful person.

The coroner's comment about the mother of Pat was interesting: "she loved her too deeply, but had become misguided". It is likely that she did find fulfilment in caring for her daughter in bed, and preparing the bandages, but it is difficult to differentiate between the love that she felt for her caring role and that which she felt for her daughter.

The mothers' behaviour may have links with the common separation anxiety that can emerge at about the time that children start school. The difficulty that some mothers have in allowing or encouraging their child to be independent and to form relationships with others is well known, and is a common reason for school refusal.<sup>5</sup>

Waller and Eisenberg adopted the term "masquerade syndrome" to describe children whose medical problems masquerade their difficulty in leaving home to go to school, and pointed out that, at least initially, it is more often the result of the mother's behaviour than the child's.<sup>6</sup> They, and others, have described the factors that can contribute to mother-child separation difficulties and several of these were apparent in the three cases that were described.<sup>7-10</sup> All three children had had an initial illness that caused maternal anxiety, and in two cases the mother's behaviour seemed to stem from that time. (It is recognised that separation anxiety is more likely with children who have genuine life threatening illnesses.<sup>11</sup>) In each case, the child was an only child and, to that extent, of increased value. In each case, the mother seems to have had a rather unsatisfactory partnership with the father, who himself was insufficiently involved with her and the child; this fact results in the child becoming more important to the mother than her husband. The fathers were unusually absent, passive, or dependent and, in one case, probably had greater homosexual inclinations than heterosexual.

Whenever the life of a child is wrecked there is a tendency to blame the agencies and services. In relation to Pat, local social services claimed that they were not able to intrude unless they were "called in". In the UK social services can force themselves on families where a child is thought to be in danger from their parents, but they are in a very weak position when that child is approaching, or reaches, the age of maturity.<sup>12</sup> Care orders last only until a child reaches the age of 18 years.<sup>13</sup> The 1989 Children Act assumes that child abuse occurs when children are under the age of 17. It does not apply to mature people, even though they may still be under the adverse influence of a misguided parent. We should recognise that childhood does not stop inevitably at the age of 17 or 18, it only stops when the parent dies. In

these cases, by the time the mother died the children were cast into a permanent role of bedridden invalidity. In later life, after the mothers had died, general practitioners were involved with two of the invalids, but even then had varied opinions about what had happened when the invalids were children. One of them commented “it’s a free world, people should be able to do as they want”. It is doubtful that many paediatricians would agree with that view: parents have responsibilities as well as rights, and children do have their own rights—to a normal life and one which allows them to develop relationships outside the home and become independent. The parental care caused considerable harm in childhood, and lifelong disability.

The National Health Service was established in 1948, before Pat’s birth, during Malcolm’s early childhood, but after Mabel’s childhood.

The early lives of all three occurred well before the 1989 Children Act.<sup>14</sup> The question that needs to be asked is whether there are similar children today being kept in bed or kept at home, and being prevented from participating in normal school and social life, and from growing up as healthy independent adults.

One would hope that if any such cases are occurring today, action would be taken by the appropriate agencies, if necessary, using their statutory powers under the Children Act.<sup>15</sup> It would be hoped that the combined approach by the education authorities and social services would bear fruit. As with all children who are missing school, the most important step is to ensure their prompt return to school.<sup>16 17</sup> Usually, school welfare officers and educational psychologists will be the key persons. On other occasions, child psychiatrists, child psychiatry day units, and paediatricians may be involved. But even today it is clear that there are major difficulties for both education and social services when the mother invokes illness as the reason for her child’s failure to attend school. There is also a shortage of staff and resources to deal with complex family problems. It is much easier for social services to address a problem in which there is forensic evidence of child abuse than one in which there is unusual and ill defined emotional abuse, even though that may be leading to lifelong invalidity and incapacity.

Patients of all ages who allege that they have troublesome symptoms, for which no medical cause is found, are difficult to deal with and difficult to rehabilitate into normal activity. The problem is even greater when a parent claims that the child is ill and yet neither examination nor investigation discloses abnormality. Both health and school authorities have great difficulty coping with parents of such children, many of whom are said to have multiple allergies or persistent lassitude, and few doubt that some children who have the label myalgic encephalomyelitis (ME) would return to school and full activity much quicker if they were not being reminded regularly of their

symptoms and their illness by the parents with whom they are living. Dealing with such cases requires persistence and resourcefulness by school authorities, health services, and social services. The closure of most residential schools has compounded the problem; they were a valuable way of establishing whether a child really was ill or incapable when on their own with other children, or whether their disability was only present in the eyes of their parent when living with their parent. There is an understandable tendency for professionals to back away from these emotive problems, and also from parents who are extremely difficult to work with. But the outcome for children who are cast into an inappropriate illness role and prevented from engaging in normal school and normal activities may be catastrophic and crippling, as these three cases demonstrate. They should make us all ponder about our own role when we encounter families in which a child is being denied the opportunity to grow up healthily.

In British society these cases generate little interest. The reports of the inquests were brief and confined to local newspapers. In one of those newspapers the front page had a banner headline: “Chained-up Dog Left to Starve” and a picture of a shepherd dog “now fully recovered after nine days of treatment”. The dog had been kept in its shed without proper care for 28 days, and “weighed only 47 lbs”—which is almost exactly the same weight as Pat when she died after 28 years in the care of her mother.

I thank the colleagues who introduced me to these families, and all those who provided further information. I thank M Jones for her efficient help.

- 1 Meadow R. Munchausen syndrome by proxy. *Arch Dis Child* 1982;57:92–8.
- 2 Meadow R. Neurological and developmental variants of Munchausen syndrome by proxy. *Dev Med Child Neurol* 1991;33:270–2.
- 3 Meadow R. Fictitious epilepsy. *Lancet* 1984;2:25–8.
- 4 Meadow R. What is, and what is not, “Munchausen syndrome by proxy”? *Arch Dis Child* 1995;6:534–8.
- 5 Eisenberg L. School phobia: a study in the communication of anxiety. *Am J Psychiatry* 1958;114:712–18.
- 6 Waller D, Eisenberg L. School refusal in childhood—a psychiatric–paediatric perspective. In: Hersov L, Berg I, eds. *Out of school*. Chichester: John Wiley and Sons, 1980: 209–29.
- 7 Levy DM. *Maternal overprotection*. New York: Columbia University Press, 1943.
- 8 Wallace HM, Siffert RS, Deaver G, Pingitore E. The home bound child. *JAMA* 1955;158:158–60.
- 9 *Out of school*. Hersov L, Berg I, eds. John Wiley and Sons, 1980.
- 10 Hersov L. Emotional disorders. In: Rutter M, Hersov L, eds. *Child and adolescent psychiatry: modern approaches*, 2nd ed. Oxford: Blackwell Scientific Publications, 1985:368–81.
- 11 Green M, Solnit AJ. Reactions to the threatened loss of a child: a vulnerable child syndrome. *Pediatrics* 1964;34:58–66.
- 12 Mitchels B. Child care law. In: Meadow R, ed. *ABC of child abuse*, 3rd ed. London: BMJ Publishing Group, 1997:65–9.
- 13 The Children Act 1989 guidance and regulations. Vol 1. *Court orders*. London: HMSO, 1991.
- 14 Home Office, Department of Health, Department of Education and Science, Welsh Office. *Working together under the Children Act 1989*. London: HMSO, 1991.
- 15 The Children Act 1989 guidance and regulations. Vol 6. *Children with disabilities*. London: HMSO, 1991.
- 16 Kennedy WA. School phobia: rapid treatment of fifty cases. *J Abnorm Psychol* 1965;70:285–9.
- 17 Blagg NR, Yule W. The behavioural treatment of school refusal: a comparative study. *Behav Res Ther* 1984;22:119–27.