

Margaret Myson

Margaret Mayson, one of three daughters of a civil servant, was born in Lancashire, and was educated at a co-educational grammar school. She herself joined the Civil Service, as did her husband, though he was in the R.A.F. when they married in 1941. They now live with their adopted son at a seaside resort in Lancashire.

Mrs Mayson's main occupation is housework, but she is a member of Toc H, and works for the Prisoners' Aid Society and the Horder Committee for Arthritics. She spends much of her leisure time reading, letter writing and listening to music. She says her former ambitions-to climb the Matterhorn, to make a parachute jump, and to have something published-have been replaced by some modified ones. She hopes to remain active until her son qualifies for a career, to hear him play a Mozart Horn Concerto, and to acquire an all-weather invalid carriage instead of her present open one.

Mind Over Matter?

(Chapter 7 in Hunt, P. (ed.) 1966: Stigma: The Experience of Disability, London: Geoffrey Chapman).

'MAN IS matter and spirit, both real and both good.' This fragment floated to the surface of my consciousness as I lay in hospital many months ago.

I was in that state of peaceful weakness which follows a period of high temperature, intense pain and complete physical prostration; I was, in clinical terms, recovering from a severe flare-up of rheumatoid arthritis. Movement of any sort was difficult and fraught with pain, so I lay thinking or, rather, drifting in thought. Poetry came readily

to mind: I love poetry and have verses stored in mind to suit every mood.

'There are sweet fields that lie
Under the mountains,
Where life runs pleasantly
Like little fountains.'

This I could appreciate; I wanted no more of life than that it should run pleasantly, but Eric Gill's philosophy of the goodness of the body seemed utterly irrelevant to my situation.

Seven years had passed since the disease, starting in my feet, was jolted into a full-scale attack when a careless motorist knocked me from my bicycle. Seven years of ceaseless-repeat, ceaseless-pain, seven years of increasing disability, with three complete physical and nervous collapses. This does not add up to goodness of body, yet somehow I felt there was truth in those words. Could I discover it? In thought I went back over those seven years; beyond that to twenty-five years of normal health; beyond that, to childhood. Perhaps somewhere along the way I should find an answer.

Born premature and underweight, I was a delicate child, suffering each winter from common childish ailments (with complications) and from other diseases not so common. Yet I was happy in my own fashion. I had my mother for company, and I learned to accept physical limitations, to bear pain with a degree of fortitude - it is agreeable to be called 'a brave girl' - and to find compensation in reading, painting and later in writing verse. True, I welcomed the return of Spring when I regained some measure of health and emerged to join my two sisters and play out-of-doors. As I could neither run quickly, nor swim, nor catch a ball, my chief delight was in games requiring imagination and

no physical prowess. After the age of twelve, my health improved and into the following years I crowded all possible physical and mental activity. In mountaineering I found the means to enjoy the beauty of nature, to think poetry and to cultivate physical endurance; I exercised the power of mind over matter and often drove my body beyond the limits of weariness. Later, after marriage, I used the same force to keep house, to work part-time in hospital and to perform jobs of welfare work. When our child came, life was full and very happy. It was on his fifth birthday that I became aware of the acute pains of rheumatoid arthritis; my feet were so swollen that none of my shoes fitted. My first reaction to the doctor's diagnosis was sheer incredulity; then the specialist told me the clinical facts, so I borrowed a medical dictionary and confirmed that this was 'a most painful and crippling disease; incurable and often progressive'. 'Fine,' I thought, 'here am I, not yet forty, a child and husband to care for and starting an incurable disease.' I was told to go home and learn to live with it! I went home and quite simply refused to recognize the facts; I was put on steroid treatment (cortisone), got a measure of relief and pressed on with my household duties, disregarding medical orders to rest. Well, I had reached this point in my meditations as I lay in the ward when a charming girl from the Path. Lab. (we facetiously called her Dracula) came to take a blood sample. From the small bottle of blood can be assessed the activity of the disease; I thought of it as the amount of evil in my blood. My blood was quite evil; yet my mind was pre-occupied with Eric Gill and his premise on the goodness of mind and body. As I pondered, I realized that though ill and helpless, I hadn't given way to despair. Twice before, I had experienced these attacks. Given the rest and care it needed, my body had responded in the past and though the pain was ghastly, I knew I would walk again. My body, though not perfect, would learn to cooperate; I should not, as in the days of arrogant health,

drive it to extremes, nor should I disregard pain as in the early years of illness. I had to learn not to despise my fallible physique, not to ignore the warnings of pain, but to use my determination in achieving co-ordination of matter and spirit. Quite suddenly I admitted that I had not been fair to my body. I began to understand, more profoundly than when in good health, the essential one-ness of the human being and that in trying to impose domination of mind over matter, I was a being in conflict. Similarly, one who allows the ailing body to bog down the mind is a being divided.

This problem of conflict is, perhaps, the greatest difficulty of the physically handicapped. If the disablement is the result of accident or sudden illness like polio, the shock must be appalling and self-adjustment extremely difficult. If the disability creeps on insidiously over the years, as in my case, the battle is prolonged and devastating.

Lying fallow in hospital I realized why, as a child, I was a 'good patient', while, as an adult, I am 'very difficult'. In childhood one is dependent upon others, one has no responsibility beyond that of obedience and the effort to acquire knowledge and contribute to the harmony of home and school life. Therefore illness, though unpleasant, though it modifies one's activities, is not a matter of responsibility to a child. To an adult, particularly to the conscientious type, illness brings legions of problems. 'Who is to care for the family? Who will maintain the home as I have done? Everything depends on me! I cannot go to bed, much less can I go to hospital; I cannot let my family down.' So the conflict rages and adds to physical malaise the torment of nervous tension. Eventually one becomes so ill that submission to medical authority is inevitable, and hospital is accepted as best for patient and family. As far as I am concerned, the battle does not end, only shifts its ground. After some weeks of docility, less the result of

sensible co-operation than of weakness, I become pre-occupied with the desire to return home; my son is obviously missing me and says so emphatically; my husband looks harassed though he says all is well. So I begin to worry; physical recovery is retarded but I return home, weak, handicapped but happy to be with my family, to care for them as well as I can.

Of course this hospitalization (horrid word) is an aspect of life which one must accept and which one's family must accept. It is hard on a child to be without a mother for long periods; it is hard on a husband. Realizing this and perhaps, in my vanity, magnifying the deprivation, I developed a strong sense of guilt; this, more than self-pity, added to my invisible burden. I felt guilty also because I could no longer do all the housework, the cooking, baking, sewing, gardening and odd jobs of painting and decorating. Before my illness, I'd done this and more besides. My husband had his work; I had mine in the home, and I never expected help. So, for nine months after the onset of the disease, I struggled to carry on as usual; a collapse followed, then came four months in a hospital for rheumatic diseases.

There I found out quite a lot about myself and about rheumatoid arthritis. The specialist told me the clinical facts: there was no cure; only help could be given. The ward Sister, a fine woman, pointed out how I had aggravated my condition and advised me to become a 'cabbage'. A nurse told me that I would recover to live a useful life but would never again climb mountains-I could have killed her for that bit of information. My fellow-patients were wonderful; they gave me understanding and the benefit of their own experience, and helped me to realize how common were my worries about home and family and my guilt complex.

All this knowledge I stored up but, headstrong as ever, chose only the advice which suited me. Having been told that climbing was taboo, I felt challenged to attempt it and while on holiday, fortified by a large dose of cortisone, I managed several climbs in the Lake District. It was foolish, but I felt marvellously triumphant. Only afterwards, when the pain and swelling in my knees flared-up and cortisone injections had to be given again, did I realize that to disobey the rules meant an increase in pain and limitation of movement. When this happened my household tasks were made more difficult; I became frustrated, conscious of dingy curtains and paint work and a neglected garden, and overcome by this guilt complex because my husband must help with household tasks. The fact that other husbands also cleaned windows, lit fires, gardened, and even sometimes did the weekly wash, was no consolation. For a long time these mundane matters oppressed me, dragging me to despair because my body simply could not obey the dictates of my will. On the level of physical rehabilitation, a great deal is done for the disabled. There are gadgets of all sorts to assist the housewife: aids to enable one to wash and dress without help; crutches, walking machines and wheelchairs to facilitate mobility. But the major problem remains that of personal adjustment to one's limitations. Vividly I recall my first appearance walking in public with elbow crutches. I'd been in hospital for Spa treatment for four months, two spent helpless in bed. I'd learned to walk again and in the security of hospital, where everyone was afflicted, felt proud of my progress. To go out alone and mingle with normal, healthy people was quite an experience, and my first hesitating venture on crutches gave me a taste of what, as a cripple, I might expect. Interest, sympathy and kindness! Noble attitudes but I remember feeling as though I was naked in a public place; exposed in my abnormality. My first encounter was with an old lady. She smiled, said, 'Can I help you dear? So sad to see one so

young (compared with her I was young) like this.' With what I hoped was carefree nonchalance, I thanked her, assured her of my ability to manage, crawled back to hospital, sought the sanctuary of the loo and wept bitterly. No doubt physical, as well as emotional, tension was the cause of my tears, but the experience shook me. Was this to be my life? How would my husband, son and friends react-my neighbours?

In due course I realized that this hypersensitive concern about 'what people would say' was a form of excessive self-interest, but the fact remained that people were interested, were kind, whilst : all I longed for was to go unnoticed. In contrast to this sympathetic concern,. I got a real booster for my morale when out for another experimental walk. An elderly gentleman, himself a , patient in the hospital, but much nimbler on his feet than I was, courteously invited me to take afternoon tea with him. We found a cafe and there were steps - torture to negotiate - but my escort made no comment. Over tea and cream cakes; in gay conversation, I began to feel normal and to forget my physical limitations.

In time one learns a technique in handling the well-meant but tactless remark, but I was surprised to find how long I remained sensitive to comment on my crutches. A typical instance occurred at a social function when an acquaintance, completely uninhibited herself, called out, 'Whatever is the matter with you?' My immediate and ignoble impulse was to make a facetious reply,

'Oh, I enjoy walking like this.' But I muttered, 'It's just the arthritis,' feeling thoroughly ashamed. I would have felt quite happy to be able to say I'd broken a leg skiing or riding, because a healthy body, temporarily maimed, is very different from a body affected by a progressively crippling disease.

A child's remark, 'Why is that lady in a push-chair?' did not worry me, but my son at eight years of age was embarrassed. 'Silly nit,' was his terse comment. I sought to mollify his feelings at being singled out as a child whose mother was 'different', and in doing so, became myself less sensitive to my disabilities. I found it a good plan to make fun of my 'wooden' legs and knobbly hands and to laugh at my struggles with girdles and tight fitting dresses - this in private of course; in public we behaved unostentatiously. One time, feeling very much aware of my limitations, I asked my son what he thought mothers were for. 'Oh, to make food and be there,' was his reply. Truly masculine philosophy, but it helped me feel less useless. One of the doctors made a similar comment when I was lamenting my inability to dash about and how it affected my family. 'Well, there's one consolation, they know where you are and that's more than can be said of some mothers.' They did indeed know where I was; either in hospital or struggling on at home.

On the whole, my husband and son have taken my affliction rather well. Like most men they have a strong sense of self-preservation, and have given me no encouragement to indulge in self-pity or to become an interesting invalid. When severe flare-ups have occurred, their help has been forthcoming and if, at times, I have yearned for a little more cherishing, such as some women get, I have done so privately. At times I have envied women with husbands who 'won't let me lift a hand,' but I've seen, in Rehabilitation Centres, how such attentions can rob a person of the ability to do even simple things for themselves, so that the process of re-education becomes more difficult and sometimes impossible. It is, of course, fatally easy to give up trying, when every movement is painful; but since rheumatoid arthritis is not a death

sentence but a life sentence, it is necessary for sufferers to hold on to as much of life as possible. For this reason, my family's behaviour has been the best for me. I have been needed, as every wife and mother. is needed, and because certain activities have been beyond my powers, I've made up by taking an active mental interest in their pursuits. I've shared my interests too, and as a result, my son, now twelve, probably knows more of C.N.D., Prisoners' Aid Societies, the 'colour' problem and politics than the average boy of his age.

So the years have passed and apart from the weeks in hospital and spells of high temperature, I have managed, with home help three hours per week, to do the housework, bake and prepare meals, to sew and paint and try to be a cheerful wife and mother.

Even when I have been half-way across the country having Spa treatment, when my husband has coped single-handed with his office work plus care of home and child, when we have been together for only a few hours every fortnight, we have contrived to have fun. True, our son complained that it wasn't very nice having a Mum who was always in hospital (gross exaggeration), that Dad was always cross (another gross exaggeration). True, my husband looked anxious at my frailty and inability to walk, yet when we were together, out in the open air, husband and son taking turns to push me in my wheelchair, we laughed and talked, keeping up-to-date with the small interests of family life. It became a ritual to go to a cafe for tea with chicken sandwiches; the waitresses got to know us and we received V.I.P. treatment; whether or not it was because we aroused sympathy but the atmosphere was agreeable and helped to diminish the pain of parting. To cheer up our son, I tried to show that life could be fun, pointing out the long train journeys, all the interesting

engines he saw, the fun of our little tea parties and the plans for the time when I should be home again.

In this way, I learned to seek for myself the positive aspects of this disagreeable phase of life and, though I cannot see any affliction as a blessing, I do not spend time or thought in wondering why God allows suffering. Sometimes I wish that I could share the belief of a physiotherapist who treated me - she was Irish and a Roman Catholic and believed that suffering was a sign of God's blessing, that only the 'chosen' were afflicted. It restored some of my self-respect to hear this view, as many of my friends, themselves extraordinarily healthy, hold opinions similar to those of Christian Scientists. I cannot believe that 'we are what we think', that negative thoughts lead to a 'faulty physique and vice versa. It did not help me to be told by a physically robust Christian Scientist that I was not really an arthritic, that she saw me radiant with health. Actually I did look healthy; my face was, and still is, pink and rounded (a side-effect of cortisone), and there was no deformity in my limbs at that time.

Other friends gave me books on Faith Healing, some of which were of great value, whilst others left me feeling guilty of wrong thinking and lack of faith because my disease was not miraculously cured. Though I have not dabbled in quack remedies such as are suggested by people who know someone who was cured by so and so, I was interested in Naturopathy. It sounds attractive; no drugs, just manipulation, diet, relaxation and no more pain. However, such treatment was dismissed as too costly. In the light of later experience and conversation with people who have tried these 'cures' I realize it was wise to adhere to conventional treatment.

To many, the life of a handicapped person may seem limited, and on the physical level this is so; but my life has been enriched by the variety of people I've met, with many of whom friendship still flourishes: hospital staff, almoners, physiotherapists, occupational therapists, ambulance drivers, home helps and the two good neighbours who rose nobly to the occasion when I lay helpless and alone. I have met these people because of my condition; and life has become more varied and fuller by these personal contacts. My friends of pre-arthritic days have been faithful; they (and my sisters) visit me whether at home or in hospital, and take me by car to Toc H meetings which are of continual interest and help to make me feel of use through service to the community.

The need to be useful, when one's activities 'are limited, can be a real problem. To prevent it becoming a source of frustration, one must find ways to serve which are within one's limitations and, in so doing, one can re-discover some talent lost, for a while, in the bustle of life. Such was my experience. When I was young and bored with my work in the Civil Service, I studied Art at evening classes, specializing in script writing and illumination. For years after my marriage I had been too busy to do any purely artistic work, but when I became unable to walk or do heavy housework or gardening, my fingers could still hold a pen and paintbrush and I still had my sense of form and colour. Though I have not yet discovered a commercial demand for such work, I've done illuminated manuscripts for friends and it has been a great joy to use creative skills. Good occupational therapy, too!

Music has been another compensation. What little ability I had to play the piano in my youth has been lost by reason of the arthritis in my hands, so my husband has bought a wonderful collection of records, mainly of orchestral works; now my solitary hours can be filled with music-Beethoven,

Mozart and Tchaikovsky. This is an indulgence which would have struck me as little short of hedonism in my active days, but now I can relax in the afternoon and enjoy 'being' instead of 'doing'.

When young and ailing I learned to love books, and read omniverously; that is a pleasure still within reach, however limited my physical activity. Even when I am too weary to read, the recollection of authors like R. L. Stevenson, Michael Fairless, the Bronte sisters and Winifred Holtby, all of whom worked against great odds, gives me courage and hope.

To compensate for the country walks which are now beyond my power, my husband plans days throughout the summer when we go on coach tours. Getting in and out of the vehicle is no problem when my husband is with me. He simply lifts me; fortunately I'm small, weighing under seven stone, and my husband is big and strong. Every one of these days stays in my memory giving pleasure perhaps more intense because there have been times when it seemed improbable that I should see the countryside again.

The garden where I loved to .work is now a delight, though for years I hated it because I could no longer dig and plant and weed. Now we have a bird-table, so with flowers and birds, grass and trees, I can enjoy nature on a small scale. If, at times, I yearn for rugged paths and mountain tops, for the thrill of the climb and the wonderful sight of still more peaks and valleys, at least I have had these and the memory is still keen. One must learn 'To see the world in a grain of sand, and heaven in a mustard seed'.

Even my dislike of depending upon others-my 'stinking pride', as one forthright friend calls it - has proved of value, because it has forced me to find a way to get about

unaided. In the early years of illness, this stubborn streak led to disaster, since it was used to force my body to the point of collapse. When used with a little intelligence, the results have been very satisfactory. In spring, two years ago, finding that recovery was slow, I began to dread a recurrence of the frustration experienced the previous summer when I had alternated between bouts of activity following the ACTH injections and periods of fever, inflammation and depression as a result of this activity. As I could not walk without pain I was practically housebound, so I brooded over tasks left undone, tried to do them, and then became frustrated when pain and weakness overcame me. So the circle went on its vicious way. Last year I no longer had the stimulus of ACTH as the evil side-effects outweighed the benefits; however, I did have tranquillizers, steroids and pain-killers and was trying to overcome my reluctance to taking these drugs.

Anyway, I was more tranquil but recognized the need to get out of the house and amongst people, otherwise I might take the line of least resistance and settle for a housebound existence. Though I had driven the family car and held a driving licence for fifteen years, we had no car now and in my condition I doubted whether I could handle one. A wheelchair was no use, because I wanted independent mobility. What I needed and eventually bought (second-hand) was an electrically-driven invalid carriage; light to handle, easy to maintain and if not a thing of beauty, wonderfully useful. My first outing was great fun. Accompanied by my husband and son on bicycles, I felt like a V.I.P. with outriders. We went to the shore, where, over the marshes and sand, was the distant sea. I felt like a bird released from a cage - yes, I'm sure they feel exactly as I did. I felt the wind on my face (a bit cold, really), I breathed deep, smelled the grass and cow smell and knew the delight of being free to move - even if at only eight miles per hour.

Since then I have become accustomed to driving in traffic, using the vehicle instead of an ambulance to attend hospital, to visit friends, to do errands and share all manner of normal family activities. Doing the errands is particularly gratifying as I am able to do my neighbour's shopping on occasions and thus repay her, in part, for the hundreds of times she has collected my shopping. My friends were glad to see me mobile; only one asked whether I felt self-conscious in such a vehicle. Perhaps I do, a little; but the delight of freedom and independence and the need to concentrate on traffic problems, prevent me from worrying on that score. I find that my home looks most attractive on return from an outing, and isn't nearly so neglected as I thought. In fact, the ability to go out, unaided and without pain, has restored the balance of life.

My intention, in writing of these compensations, is to show how I have been helped to come to terms with, my disability. Personal qualities and past experience can be used to help or to hinder one's 'rehabilitation. Thus, my early years taught me to accept physical limitations and find ways of enjoying life through books and crafts; the determination to succeed on some level (mountain-climbing) helped me to walk again and become useful, after that same determination, wrongly used, had encompassed my downfall. So I see a pattern in life, where our present is made up of our past and our future is built on our past and present; where every disaster is a challenge and a discipline, and where the handicapped person has a contribution to make. I would hesitate to say that it is God's will for some people to be disabled. In fact, the only positive thing about disablement is, in my opinion, that we who are handicapped can be of some use to other sufferers; we can tread where the physically perfect cannot usefully tread.

My experiences in the hospital for rheumatic diseases taught me a lot. I'd had contact with disabled ex-servicemen when doing welfare work, but it is quite different to be disabled and find oneself one of a large number of people variously crippled, resident in a hospital for Spa treatment. I half expected to find each one a noble soul, bearing affliction with fortitude. I found them to be people with normal characteristics, just a cross-section of humanity. There were the courageous ones and the moaners; those who talked endlessly of their affliction and those who never mentioned it; there were those with a happy home-life, those with sadness and disillusionment to bear; those who were cherished and cossetted, and those who struggled alone; some were dispirited, some were gay. These gay ones I liked; even though rather serious myself, I enjoy gay company, and to my surprise I had some hilarious moments in this community. After this, I never dared to feel sorry for myself; who could, knowing of others so much less fortunate? I was helped, not only by examples of fortitude, but by the wise normality of the well-integrated people.

However, it was in someone I had known for many years that I found the shining example of courage. This was a man who at twenty had been blinded and lost his hands and the hearing in one ear; he was a research chemist, and his injuries were the result of an accident in the laboratory. It does not take much imagination to picture the horror and despair of that young man. Now, in his "middle forties, he is the most cheerful person, interested in books, politics, music and in life generally. He is a gifted singer with a repertoire of some five hundred songs. To think of him is an inspiration, but he would hate to be told so as he loathes pity. I have not yet attained this serenity and wonder if I ever shall. The nature of rheumatoid arthritis, which is a disease of the whole body, makes each day unpredictable; one is 'up and down like a

perishing yo-yo' as one of my fellow-sufferers expressed it. This makes it impossible to plan events, or if one plans, there is the risk of disappointing others; in time one learns caution in making promises or one pays the penalty in increased pain. I am not, by nature, cautious, so this was a lesson I had to learn from experience. I'm also fond of a well-ordered life, with a routine for the less inspiring household tasks; in this respect I have had to modify my ideas, but only after years of suffering because I would continue to 'wash on Monday, iron on Tuesday, etc., etc.,' regardless of inflamed joints. Now I am no longer under that compulsion and to my surprise I find that, with tensions relaxed, life is less of a battle and the work gets done in due course.

Even writing this essay presents a problem, because one must be reasonably vigorous in order to make any effort. To co-ordinate thought and express it in the written word requires a great effort for the average mind, and when that mind is dulled by pain the effort becomes impossible. So one must write on one's 'better days' thus giving a picture which is scarcely representative; on the other hand, to dwell only on the misfortune of a physical handicap would be equally false.

Acceptance of my disabilities has come slowly, and even now I transgress daily, but I have tried to learn from the courage shown by so many others. Such courage does not manifest itself by a constant head-on clash with circumstance, but by faith in God and by intelligent seeking for means to express oneself, to serve and to create -very humbly in my case. I should hate to give the impression that I think I'm qualifying for a halo or that I'm noble or courageous. Occasionally, people have said to me, 'you are wonderful to be so cheerful', and so on, and I've squirmed inwardly and thought I would rather be a healthy normal being than an afflicted saint. Quite

seriously, though, I have profound faith in God and in prayer; I have faith because only faith has helped me in the most difficult times. When weakness, pain and despair have been almost unbearable, when coherent thought has been impossible, the words, 'God help me,' have brought peace. Though I cannot at present share the philosophy expressed in the words of 'The Blind Ploughman', so beautifully sung by Chaliapin, perhaps if greater trials lie ahead, I will be able to say:

Set my hand upon the plough,
My feet upon the sod,
Turn my face toward the East,
And praise be to God.

God, who made his sun to shine
On both you and me;
God, who took away my eyes
That my soul might see.