

## **Margaret Gill**

Margaret Gill was born in 1923, and contracted polio at the age of four. She was in hospital for two years for a series of remedial operations, but was left with a partial paralysis of her limbs and a spinal scoliosis.

Owing to long periods of ill-health during childhood Mrs Gill's education was sketchy, but this has been remedied to a large extent by copious reading. For twenty-two years she worked in the X-ray Department of a County General Hospital, and was personal secretary to the Senior Consultant Radiologist when she wrote this essay. In November 1965 she married the Rev. Robert Gill, rector of Hertford parish church.

Mrs Gill has written scripts for parish entertainments and hospital concerts. Her special interest is cooking, and she is also a keen photographer and artist.

## **No Small Miracle**

**(Chapter 8 in Hunt, P. (ed.) 1966: Stigma: The Experience of Disability, London: Geoffrey Chapman).**

'Deformed, unfinished ... that dogs bark at me as I halt by them.'

MOST OF US will recognize this quotation from Shakespeare's play Richard III. Poor King Richard, to possess so much by position and power, and yet to find so little to sweeten the bitterness of disablement. No one to trust; no one to care for; and no one to care for him in return. Leaving aside the historical drama of the play, I am always impressed by Shakespeare's apparent insight into

the thoughts of the disabled. The bitter acceptance of his disablement shows again and again in Richard's speeches. I do not suppose for a moment that dogs actually barked at him, but such an exaggeration is rather typical of the disabled. We tend, when very despondent, to exaggerate our deformity in the hope of hearing our exaggeration contradicted. We speak disparagingly of our physical appearance, hoping that our listener will give the right answer—the kindly, slightly flattering one that soothes our sore heart and boosts our shaky self-confidence. One often finds, however, that a frank appraisal of one's appearance gets a frank answer in return: and illogically we don't like the truth, and the bitter weed of self-pity, latent in all of us, healthy and disabled alike, grows a little stronger.

I think it very difficult for anyone disabled in early childhood to avoid being spoilt. A handicapped child is almost always surrounded with love; encouraged and praised for each step forward; flattered and applauded for any progress he makes. Frequently the praise received is quite out of proportion to the success achieved. One might be thought correct in saying 'rightly so', for being disabled is very hard work, make no mistake about it, and the victim needs all the encouragement he or she can get; but it does lay the foundation stone of pride, and the child grows used to praise and adulation. The very early school years may not be so painful to his self-esteem; but later on the disabled child comes up against the harshness of 'normal' society and the cruelty of other children. And here, for perhaps the first time in his cosseted life, he becomes conscious of the shame of disablement and the knowledge of being different'.

He finds other children just can't be bothered to give him the praise and encouragement he is used to, and the first rebellion at disablement creeps in. The 'I wants' of

childhood become 'I want to be normal'; 'I want to run in the races, play football, netball, tennis, like the others'. The reply from his classmates is invariably the hard truth: 'We don't want you; you are too slow; we shall never win if you are with us'; and when it is time to 'pick teams' the disabled child is always left until the last. Sitting on the side, watching and brooding, the only comfort is the precious thought -wait 'till I'm grown up; I'll show them then I Because one will be better when one is grown-up: a child accepts this as an automatic fact.

I myself never doubted for a moment during those lonely periods of watching other children play that I would indeed be cured when I grew up. Then I was absolutely certain I would swim, dance, play tennis, and (here the inborn vanity of the disabled is shown) I would do all these things better than anyone else. I rather thought I'd be a ballet dancer when I was older. All the discomfort of the ordinary everyday living of the disabled - the indignities of boots, calipers, spinal braces, crutches and the like - are accepted because, to the disabled child, they are only temporary, and the freemoving, active world of the healthy is only just around the corner.

At this period of development the child will tend to seek some form of relief from the burden of being disabled and unwanted, and will often find the way of escape in a dream world. He finds compensation for his enforced loneliness in a world of dream people, where there is no pain and where he or she is beautiful, brave, clever, popular. Such a world can become so real to the child that he could describe his dream friends and companions in painstaking detail. Whenever the 'normal' world becomes too hurtful the child can escape into this dream society where he feels needed and wanted and, above all, 'normal'. However, dream worlds don't help anyone to adapt himself to the hard work of making his way in

society, and while it perhaps helps to make life more bearable for a time, such escapism is useless, and indeed harmful to progress. Fortunately most children only seem to need it for a short time, and as they grow older dream people, though pleasing, are discarded for real life.

Few parents of a disabled child realize that it is essential for him to become integrated into normal society at a very early age, if at all possible. If the child is encouraged to mix with other children and, within reason, permitted to suffer the normal rough-and-tumble of life, then the need for a dream world may never arise.

In passing, it is an interesting fact that often a disabled person is a 'normal' person in his dreams, walking and running and completely free from deformity'. I have never once dreamed of myself as disabled in any way.

Unless the growing child is very fortunate in his companions, there is a still more unpleasant period to face. Older children - the nine-year-olds and upwards - can be extremely cruel to one who is different. It's great fun to jeer and shout insults at a lame child limping in the streets. It is possible to throw stones at him if there is no one looking, and he is the perfect target, because he can't run away. It is always possible for a 'normal' child to get the last word in an argument, for he soon finds there is nothing more satisfying than to shout a final word-and run away! Once again the inability to move brings another wave of frustration and impotence.

From here on in the child's development the shame of 'being different' can turn into real bitterness, so well expressed in another of King Richard's speeches: '... so mighty and so many my defects...' The contrast between the harsh reality of the outside world and the comfortable cushioning the child received at home is very, very great.

It is extremely difficult to know how to deal with the question of the bullying of a disabled child. It's no good the teacher asking her class to be 'nice' to him. The reaction of most healthy young children to this is to wait until a suitable opportunity arises to stand in a row in front of the disabled one, and the conversation can easily be imagined: 'We've got to be nice to you - Teacher says you're different'; and the end result is worse than the first. I don't think bullying by the spoken word can be controlled, and it is really another occupational hazard that the disabled have to get accustomed to.

One wonders if special schools are the answer; but I doubt if such schools for those who are only partially disabled would help much. The very disabled child might greatly benefit, but the less handicapped one will eventually have to make his way in a normal world and earn his living in it, and will probably not gain much by being sheltered from bullying during his school years. Sooner or later the child must learn to stand up for himself and, although bullying and taunting can cause bitter hurt, the path of disablement doesn't grow any easier by his being protected too much along its way.

An essential point is that the child should never be made to feel that he or she is a burden or an unwanted expense to his parents. Even in these days of the National Health Service, caring for a disabled child can be costly, and although few parents would reproach their child for being an expense, unless they are on guard, casual conversation in front of him will too easily give him the idea that his 'being different' costs a lot of money. Much silent unhappiness can result from a careless word.

A little should be said here about the power of disability. An intelligent child soon learns that a pretence of pain will sometimes divert parental wrath, and can be used most

successfully to gain his own way. Most disabled children seem to grow out of this phase - it's cheating and dishonourable, and soon abandoned - but one who perhaps does not receive enough love may grow fond of this power. In later life such a child comes to terms with his or her disability by ruthless effort, channelling pain into power; determined to succeed in spite of all physical limitations - to get to the top, no matter whom he may hurt on the way, in an all out effort to prove himself as good as, or better than, his 'normal' fellows.

During teenage years, with the intensity of feeling usual at this time, one can be filled with a bitter loathing of one's disabled body that really has to be felt before it can be understood. Companionship is essential, and integration into normal society alleviates a great deal the psychological pain of deformity.

For the completely chairbound and inactive disabled, membership of a society of fellow-sufferers may be a great help, but the partially disabled person, who is able to get about and compete for employment in the able-bodied world, needs to become part of 'normal' society and not isolated among his own kind. I believe partially disabled people find it more difficult to become adjusted to society than those who are more severely afflicted. One is so much nearer normality - yet so far from it.

One does, of course, build up a shell of self-defence through the years. One learns early in life that the disabled are often thought to be courageous, patient, cheerful, happy people, with some special talent sent to 'compensate'. One of the special 'extras' one actually does develop is, I am sure, a sense of humour. We'd be lost without it. One learns to laugh at difficulties, to cut one's losses when setbacks come along; and the reputation grows: 'He's such a cheerful chap-never grumbles.' This,

of course, is not strictly true. We are only human, and we all grumble and complain, as our patient relatives know; but it is possible to build up quite a convincing facade of cheerful bravery over the years, and a sense of humour does help immensely. Just as an acrobat learns how to fall correctly, so the disabled person must learn the art of falling over. Heaven knows he'll get enough practice at it, and must attain the ability to recover both from the fall itself, and from the humiliation of falling. In my slightly more active youth I've fallen in all sorts of odd places, but the ability to see the funny side of such occasions soon heals the feeling of shame at having made an exhibition of oneself. During the winters of the last war, as I slithered and fell on my way to work, I was almost invariably hauled to my feet by some kindly soul who would say, 'Oh! you poor dear - was it the bombs what did it?' I felt I was letting the side down by saying the havoc was caused merely by a polio germ and not by Hitler!

The pace of one's life is often slower than that of one's contemporaries, but this can have its compensations. One has time to 'stand and stare', to look around, to think. Leisure activities are somewhat limited by the measure of one's ability to get about, but in the sphere of music, painting, and writing, it is often possible for the disabled person to obtain release from the chains of disablement, and move freely in such circles, on equal terms with able-bodied enthusiasts. There are many and varied opportunities here for the disabled person to excel, and thus earn himself well-merited praise-a fair exchange for the false flattery of his childhood years. ..

Self-confidence is a very delicate plant, and its growth in someone with a handicap is easily impaired or, indeed, killed. Here 'normal' society is frequently at fault. For instance, when the disabled person becomes a member of a club, he is welcomed, everyone is very kind and he is

apparently a well-integrated member. But when it comes to deciding who is to make the opening speech, take the chair at an important meeting, propose a toast at a dinner party-then often the disabled person finds that 'normal' society is ashamed of him. The reaction is usually: 'Good Lord! Couldn't they find anyone better than a cripple to represent them?' If your fellow members can boast of your wealth, power, or position, then disability can be clothed-made decent-by such attributes. But for ordinary Mr John Smith, disabled, too often comes the realization that he is a kind of skeleton in the cupboard, to be kept tidily out of the way when important people are about. Once again there is the bitter realization that one is 'different' and with it returns the old urge for power.

If one is able to obtain employment in competition with the normal healthy world, one must be prepared for the fact that because you are disabled employers almost always expect you to work just that little bit better than your able-bodied companions. If the disabled employee is not first-class, then any mistake he makes is at once put down to his disability. His work is not classed as slipshod because he is lazy-as it would if he were a normal person. The classification is-poor work because he is crippled, unable to work well. Once a place has been won in the competitive world of industry, and the disabled worker has proved his worth, things are easier, and with a fair employer worth is recognized and rewarded. But the battle doesn't end there, unfortunately, and the stigma of disability will always be a hindrance to real progress. The disabled person often finds himself passed over in the matter of promotion for younger, maybe less efficient, but 'normal' people. Really, the whole balance of life is against the disabled. If you drive a car, then your Insurance Policy is loaded. If you are unfortunate enough to become involved in a road accident the statement, 'of course the driver is disabled. ..' tells against you at once. Life is much

more expensive. Clothes may have to be made-to-measure, special shoes and supports may be needed. Any deviation from the simple styles obtainable under the National Health Service is costly-but style and fashion mean so much to a young person. One pays dearly indeed for the privilege of disability.

It was once suggested to me by a healthy young woman that the vocation of the disabled was to provide a training ground for the able-bodied in compassion and the ability to care for others less fortunate than themselves. Just try telling someone pushing himself along in a wheelchair that his disability is a vocation sent for the use of able-bodied people, and I venture to suggest that you might quite deservedly get a rude answer.

It is hard always to accept help and sympathy gracefully - particularly the gushing sentimental sympathy of the 'Sweet little face. ... poor little thing' variety. So many people seem to have the idea that physical disablement always carries with it some form of mental incapacity as well - and it is galling to be spoken to in the tender terms usually reserved for pet dogs and cats. However, there are usually kind intentions behind all this, and the disabled generally learn to 'suffer fools gladly'.

Another irritating habit of 'normal' people is that they invariably think the disabled rather deaf, and it is at times amusing and at times humiliating to hear oneself discussed in not very soft whispers on the bus or tube. Shattering descriptions of one's deformities are coupled with equally shattering ideas as to how one reached such a condition. During the war years, as I have remarked, the reason was 'the bombs'. At the moment 'atomic radiation' is mentioned a good deal. I've not yet heard 'the sputniks' blamed; I am sure it is only a question of time!

How then, does the average disabled adult cope with his twin disability-the obvious disfigurement of body, and the hidden disfigurement of personality. Does he reach adult life toughened, cynical and disillusioned? Surprisingly, the answer is usually no. Human beings are extremely adaptable, and the hard work, pain, disappointment and frustrations of disablement, are generally dealt with in a way that is no small miracle-especially when one realizes that increasing age invariably adds to, not lessens, the burden. What is it that enables them to overcome the difficulties and setbacks of their journey through life? Above all else, love given and received.

The very best medicine that can be given to a disabled person is the knowledge that he or she is wanted. For a woman the best possible sweetener to bitterness is to be loved and needed; to be able to care for and love a man who 'forsaking all others' as the Marriage Service says, has chosen her. I think the other great healing power is faith. Everybody needs something to hang on to in dark days. There must be a meaning and a purpose in suffering if we are to endure it, and that purpose and meaning, and the power to bear disability, can only come from God. In the Bible we read that disability' has been with us through the centuries; but we also find there the comfort and help we need. One could list quotations to fill a book. Perhaps one of the most apt comes from the Prayer Book version of Psalm 56: 'Nevertheless, though I am sometimes afraid. ..I have put my trust in God and will not fear what flesh can do unto me ...'

I started by quoting Richard III. I end by quoting another man who also had much pain and bore many of the problems of the disabled with patience and courage. In his first letter to the Corinthians, in the thirteenth chapter, Saint Paul writes ' ..in a word, there are three things that

last for ever; faith, hope, and love; but the greatest of them all is love. ..'

On reflection, love is exactly what King Richard did not have!