

Mona Younis

Mona Younis was born in Jamaica, of Lebanese parents, in 1941, and is one of five children. Her parents took her to America at the age of two, where she was diagnosed as spastic, and she later spent a year there in a special school. When she was twelve she came to England to the Puckle Hill School, which was then the only school in the country for older spastic children.

Miss Younis later spent six years at the Thomas Delarue School before returning to Jamaica in 1961. However there were few opportunities for her there, so she came back to England in 1963. She went to a Spastics Society centre, and last year moved to another which specializes in further education for spastics.

Miss Younis has passed four G.C.E. subjects at O Level, and is now studying for A Levels in English and Book-keeping. Amongst her interests are reading, music, the theatre and art appreciation.

The Way I See Things

(Chapter 10 in Hunt, P. (ed.) 1966: Stigma: The Experience of Disability, London: Geoffrey Chapman).

IF ANYONE had asked me when I left school at the age of twenty what my greatest ambition was, I think my answer would have been: 'To get a job and earn my own living.' Every thinking person, whether handicapped or not, likes to feel that they are earning their own living; it is as if by doing this we feel we can hold out heads above water in society, we can compete with the outside world. I know from my own experience that even the most severely handicapped people entertain the hope, especially just

before leaving school, that one day they will find suitable employment.

I have not given up the idea of a job, because I think this may be possible for me later on in life, but it is no longer as important to me as it was. Now, three years after leaving school, my answer to that same question would be quite different. I would say now: 'To live my life to the best of my ability; to put the most in, and to get the most out.' I do not know which answer has the more virtue, but to me that isn't the point. Some day I may have a more clear-cut ambition, but I think this present ideal will always lie beneath everything I do.

Handicapped people are sometimes asked whether they accept their own handicap. I find I cannot give a complete answer to this question, even to myself. I suppose my true answer would be 'no'. I know I will remain a spastic all my life; I was born one and will die one. And I know that because of this' there will be certain things in my life I cannot do, or hope to do. But this is as far as my acceptance goes. There are other things that seem quite out of my reach but which I cannot and will not give up. When I have tried to do what seems impossible, people have said to me, as they have said to other handicapped people like myself: 'Stop knocking your head against a brick wall. Accept the fact that you cannot do it.' My answer to that is that I will simply try to knock a hole in another pan of the wall, and if I don't succeed, then I will try yet another pan of that same wall!

Yes, this is a fault, but I think it a necessary fault for anyone with a handicap, because once you accept defeat, life becomes meaningless. This attitude can cause a lot of pain; it has done so in the past, to me, and to those who love me, and I expect it will in the future. Yet if you accept

your handicap completely, you stop fighting against it, and as a result you don't learn to overcome it.

Life to me is a big challenge, and this is something I have gained by being handicapped. Just because certain things, such as simply feeding oneself, seem so far out of reach, when' these tasks are accomplished they are valued so much more. Over and over again, I have got utter joy from succeeding in something which had seemed impossible at first. I can remember with joy the first time I went shopping on my own; I went into Woolworths so that I did not have to do much talking, as my speech at that time was poor. I can remember the thrill I had when I heard that I had passed my first G.C.E. subject, a thing I had thought was beyond me.

Of course the only trouble with this way of thinking is that we have got to know when to put the brakes on. It is so easy and wrong to live in a make-believe world. It would be hopeless for me to say that one day I will be able to hold down a job, and run a family at the same time. I could not. I have somehow to adjust to my situation and come to a compromise with myself.

If ever friends of mine had a handicapped child, and came to ask what I thought would be the best way to bring him up, my answer would be that they would have to know when to treat him as a normal child, as just a member of the family, and when to treat him as someone needing special attention. Just because a child is handicapped it does not mean he has to be given everything he wants. Parents sometimes feel that in this way they can somehow make up to him for his handicap, but they are only spoiling him. On the other hand, it would be wrong not to take the disability into account, and to expect too much of the child. He will have to learn to live within the limitation of his handicap.

I often think that you miss a lot in life if you have no brothers or sisters, and certainly this is true in the case of a handicapped child. Although brothers and sisters can be very loving towards one another, they can be cruel as well. This I think helps a handicapped child to learn to 'be one of a group. I know I owe a great deal to my brother and sisters who gave me as good as they got. I am still very sensitive, especially about things concerning my handicap, like so many other disabled people, but I think I am far less sensitive than I would have been if I had not had sisters and a brother to tease me.

Parents often feel some resentment when they are faced with the fact that they have a handicapped child. 'Why does it have to happen to me?' 'What has my boy done to deserve this?' Of course this is a natural reaction when faced with such a big problem. The point is not that these feelings exist, but how they are allowed to develop - whether the parents bring them out between themselves, or pretend that they do not exist at all. I think the atmosphere in my own home is a lot freer because my family and I can argue quite openly about our feelings.

Too much importance is usually placed on the physical progress of a handicapped child, and not enough on its mental and educational development. Parents of handicapped children tend to think that if their child could walk or feed himself all their problems would be solved, instead of accepting the fact that they have a child who may never do these things, but who can nevertheless develop as a person in his own right. Sometimes it might be necessary to send the child away to boarding school to get the best results.

As I am still young, and have a lot to learn, I can only judge from my own experiences. However, I am thankful

that my mother, who saw I had no future in Jamaica (being Lebanese), left me in a boarding school, alone, and in a strange land, at the age of twelve. My parents were expecting mostly physical improvement, but what they got was much more mental improvement than physical, and this I consider my greatest treasure, for it was then that my life had a new beginning-which was to make me into a person with a handicap, and not just a handicapped person. I am sure many other handicapped people who have had the opportunity to go to school and receive a near-normal education feel the same way. My education started late, but I was still one of the lucky ones; and those who start at a very early age will obviously benefit even more.

At school we were constantly being told that it was better to be socially acceptable than to be able to walk. While I agree with this statement, I disagree with over-use of it. The amount of social acceptability we can obtain depends to a large extent on the type and degree of the disability. But surely it does not matter how badly handicapped we are as long as we are at least able to hold an intelligent conversation with people who share our interests; and by doing this we can achieve something worthwhile in life.

When you enter a room full of handicapped people you are sometimes shocked by the severity of the different types of disability even if you are handicapped yourself. But when you get to know the people in that room, their handicap suddenly seems to disappear and they become individuals; you are looking to their personality rather than to their physical appearance.

For some, being handicapped not only involves inability to walk or use one's hands, but having a speech defect, or no speech at all. If I had to choose between not being able to walk or having a speech defect, I would certainly

choose not being able to walk. Most people immediately think that because a person cannot speak understandably, he is mentally retarded or deaf. Time and time again I have come across this difficulty; time and time again I have heard handicapped people, especially those with no speech defect, comment on this. Of course I can understand the public's reaction to this problem. A first encounter with someone whose speech is unintelligible, who makes what seem to them funny faces, and who dribbles, naturally produces a reaction of 'How can such a person have any brain at all?'

Through the work of the National Spastics Society (I mention this society as it is the one which has affected me personally, and whose work I am most aware of) a great deal has been done to make the general public aware of spastics. The word is no longer unheard of by the majority of people. The spastic of today has a much better chance than the spastic of, say, twenty years ago, educationally, medically and socially. I have only to compare the reception I get here in England with the reception I get in Jamaica, where the word spastic is still almost unheard of, to appreciate how far we have come in the last ten or fifteen years. This is very good, but we have still a long way to go. Spastics, and I am sure other physically handicapped people, are still having to face the public unwillingness to accept them as normal human beings. We get stared at and told we shouldn't be allowed out; or taken as fools.

Still, there are also many people who are always ready to give a helping hand. Sometimes we tend not to appreciate this, and shrug off offers of help with, 'I can manage, thank you.' Of course we like to be independent, and don't want to cause other people trouble, but we forget that we often hurt them by not accepting their assistance, even when we do not need it. This was brought home to me

very forcibly when someone went to hold a chair for me to sit down, something I am quite capable of doing for myself. I told him politely that I was able to manage. Weeks later I learnt how much that person was offended by my refusal of help. Now I try very hard to accept offers of help, although I still find it difficult.

Like anyone else, a handicapped person not only likes to feel wanted, but also to feel needed. Many people, non-handicapped and handicapped alike, at times feel that life seems to wander on hopelessly and aimlessly, but this feeling can be more acute in us because we are so often on the receiving end of life. People may try to do everything for us, to make us as happy as possible; and, when we fail to be content with the things they hand us on a plate, they may think this is just ingratitude. Of course we are grateful for people's help, and without it some of us wouldn't get very far; nevertheless we want to lead useful lives in spite of the barriers which confront us. This is one of the biggest problems we have to face.

My need to be useful has been solved, for the present, in the spastic centre where I am living now. Here I have opportunities to carry on my education, to live a free, independent, and useful life within the limits of my handicap. Of my own free will I left my home and the people I love dearly to come back to England, because I believe that in this way I can live as full a life as possible.

Throughout this article I have tried to present a picture of the difficulties and feelings of all handicapped people. But I do realize that because I am a spastic, and because I have not had much dealing with people with other disabilities, I have been writing mainly from the spastic's point of view. I am sure, though, that other types of handicapped people must have similar problems and needs. (I have never been normal, so have not attempted

to discuss the problems which may arise from becoming handicapped after having led a normal life.) I have tried through. out to present a picture of the way I see things'. Some of my ideas may be wrong; others may have coped differently with the same problems. I have only written down here what I honestly feel and believe at this present time.