

Dennis Creegan

Denis Creegan is forty-four and was born in Coventry. His parents moved to Northampton when he was ten, and he won a scholarship to the grammar school there. He went into the gas industry on leaving school, but. joined the Army in 1940 for the duration of the war. His marriage, VE-day, and the discovery that he had muscular dystrophy virtually coincided.

After a jobless period on Merseyside, Mr Creegan joined the hospital service, in which he spent thirteen years. He now works in an Education Office in Cheshire. He has a teenage son and daughter.

Adapt or Succumb

(Chapter 9 in Hunt, P. (ed.) 1966: Stigma: The Experience of Disability, London: Geoffrey Chapman).

IT IS astonishingly difficult to give cohesion and sequence to the thoughts that have crossed my mind about disablement during the twenty years since muscular dystrophy first began to alter my life. They have lacked continuity, and been random and sporadic. In writing as a disabled person, my conclusions are drawn from a multitude of minor successes and failures, of exaggerations and disparagements; as such, they must lack the objectivity of an uninvolved observer. However, though this observer could hardly succumb to the temptation to fall back on personal instances, he would never really come to grips with the deeper problems involved. There will, I fear, be a rather complex muddle of the personal and the general in what follows.

With some shame, I have to admit that at twenty-three years of age I had neither knowledge of, nor interest in,

the broader social ramifications of disablement. One day in 1944, I 'tripped over a stone that wasn't there'; and so it all began. Invalided from the Army after five years service, there followed for me a slow, insidious deterioration until the disease seems to have arrested. My ignorance was, I suppose, unexceptional. And personal interest only grew in inverse proportion to my physical condition, as did my fellow-feeling with others disabled who, I learned, trod as thorny a path as mine. I claim no credit for enlightenment!

A number of things have stimulated consideration of the plight of others. For thirteen years I worked in close contact with the hard of hearing, and learned about problems vastly different from mine. A friend who is both blind and a physiotherapist has wide experience of various disabilities. An active acquaintance was injured and became suddenly paraplegic. A young relative was hospitalized on the verge of diabetic coma. The thoughts that follow, which I hope will have coalesced into a point of view, have probably been given direction and purpose by such people and events. How much the result would have differed had I not become disabled is hard to say. My essential 'self' and inherited temperament are unaltered. But environment, which includes the body, must prejudice one's outlook: and the parts are inseparable. Without disability, I would have been a person other than I am, which is inconceivable.

The impact of disability upon individuals follows no logical pattern. Disabled, one can consider the ensuing problems from an interior and private point of view; one experiences fascinating confidences from others disabled; and the result should be a fairly comprehensive picture. At this time, I look back, still far from the Celestial City, upon a Bunyanesque pilgrimage. There has been a fair measure of adaptation to circumstances. In moments of conceit, I incline to speak as if I had followed some brilliantly

conceived master-plan for progressive adjustment with absolute single-mindedness towards inevitable success. But anyone can rationalize past events! More accurately, there has been a continuous process of fairly arbitrary trial and error; of blind alleys and exasperating frustrations; and stubborn and often subtle refusal to accept clear facts. That is to say, I am as I am in spite of myself rather than because of myself.

Yet surely there must be means less prodigal of psychic energy of reaching the calm place within the reefs. Some who read this may have found such away. Others will be reassured to learn that here is known and traversed ground, and though everyone has to tread a solitary 'via dolorosa', someone else can vouch for the merit of keeping stoically on in the promise of a goal (because we live more intensely) even more valid than for those not handicapped.

Society has to realize actively that first and foremost we are people equally with the non-disabled. Our social needs and aspirations are identical with theirs. This obvious fact so often remains outside our awareness. There is the unnatural division of Them and Us; the same which divides rich from poor, black from white, clergy from laity, and numerous other invidious possibilities. Though our actions may not ultimately be influenced by such comparisons, the effort of will needed to ignore them has inhibited the spontaneity that should leaven human relationships. Thus disabled and non-disabled tend to become unnaturally separated. The former believe that no one can ever understand their problems: the latter shy away, perhaps not knowing how to communicate, perhaps fearful of causing unwitting hurt, perhaps even afraid of someday finding themselves in the same boat.

Though I deplore any separation of a group from the community, I think one special category should be mentioned. These are the members of families which include a disabled person. For they are peculiarly involved and yet objective. They have enhanced perception of the problems of disablement: they have to have, often knowing us better than we know ourselves. Perhaps only rare individuals have a natural gift for empathy with others, but our families must develop the power after long and painful heart-searchings. If they are to be real families, they are all partially disabled socially by the effort of remaining a unit. Sometimes their feeling of helplessness can be more painful than actual suffering: and to stand aside when self-help is the only effective long-term answer must be agonizing.

The disabled are as representative a cross-section as one could get, and an equal diversity of disabilities is superimposed upon our diversity as people. The common bond of 'being disabled' links us all in a shared experience; but the kind and degree of disability will obviously influence the practical steps required to minimize its effects and as far as possible compensate for it. The presence or absence of physical pain is an important conditioning factor. Health workers know how continuous pain weakens character. Sudden and intense pain is protected by merciful unconsciousness: but continuous pain, even at low intensity, wears one down. Moreover an acute awareness of one's condition must in some cases be tantamount to pain in terms of mental anguish, although for others of different temperament it can be a stimulus for personal development.

Most of the disabled, initially at least, have a healthy mind in an unhealthy body. This provides a good prospect for learning to cope successfully with limitation. Much depends on when and how the disablement came about.

One starting in infancy, though demanding more of teachers, affords an excellent opportunity for adaptation, providing sight, hearing and speech are unimpaired. (Where this is not so, complex and special difficulties exist for social integration.) No recollection of a full life brings intermittent nostalgia. For those disabled later in life, memory can be a stimulating compensation, if the 'obvious injustice' of life does not cause bitterness.

Some disabilities, of course, can be hidden, whilst others cannot. Probably, from a social point of view, a simple facial disfigurement is the worst disability of all - the quickly suppressed flicker of revulsion is, I am certain, quite shattering.

If disability is relatively slight, there is a temptation to 'pass for normal' rather as some coloured folk try to pass for white. But this is to attempt to deny the truth, to evade an issue which cannot be avoided indefinitely. 'I will,' says the spirit of bravado, 'nevertheless be normal.' The word 'normal' has a glorious sound. Yet a 'normal person' has no more real existence than an 'average man', however useful he may be for statistical computations. Normality is a donkey's carrot, a tantalizing goal forever unattainable.

It is said that we begin to die the moment we are born. The process of degeneration is certainly common to all, since sooner or later some disablement comes in the natural order of things. A progressive disease will directly accelerate this process through its symptoms and through the increased strain these engender. A static disability due to accident, or sudden illness such as poliomyelitis, results only in increased strain. The pressure of these things is infinitely variable-progressive disease may make a decade to undermine the person at all.

Disablement as a problem is divisible into two linked parts- the psychological and the practical; the things which go on inside, and those done by, through and for those disabled. If the spirit in the cage fails, no amount of external effort can achieve anything. The former is by far the more important, as it predisposes the latter to success or failure. So let us think about the philosophy of disablement. This can mean many different things to those who are bound only by the common thread of an understanding, drawn from their experience of special physical limitation for which the material edifice of society has not been constructed - for economic reasons, the needs of the majority over-ride those of the minority.

I think the first philosophic need is for an acute sense of proportion and an active sense of humour. Until we can laugh with others at ourselves, our disabilities will dominate us. The only reasonable outlook thereafter seems to me one of philosophic detachment in a spirit of adventure, with some sort of religious faith.

But what sort of religious faith? Being disabled, we cannot run away from the burden of existence; nor try to; nor deceive ourselves that we are succeeding. Lip-service religion cannot help; only something that has practical validity for us, where the truth shines unmistakably through, can do that. But as Pilate so succinctly remarked: 'What is truth?' This sort of consideration may be stimulated by the scarecrow's function of simply keeping still, which provides ample opportunity to think, and think, and think. ..

For good or ill, I had no preconceptions, no prior indoctrination; and there were no outside pressures. Posing the inevitable fundamental questions of 'Why?', 'Whither?', and 'Whence?', I sought a satisfying synthesis which would give some point to the influence of

disablement on the apparently insignificant life of a single 'soul'. There was no personal revelation and no sudden moment of decision.

Such questions have little importance for those leading a continuous extrovert life. These are the 'doers', the venturesome ones, who offer the disabled so much vicarious pleasure. Their narrative accounts of things we cannot do (and to be honest probably wouldn't anyway), provide us with endless compensations. At a stage when 'doing things' might inhibit further enquiry, the disabled are forced into themselves, and their development - possibly right out of character-brings them back to the same fundamental questions.

We philosophize in a most unscientific, arbitrary, way. Few of us are scholars; indeed physical restriction makes scholarship difficult to follow. So we think rather haphazardly. Unless each brick in our building can separately be proved valid in everyday life, proved relevant within our circumscribed orbit, the building is unfit for our habitation. Perhaps excellent health is necessary for the consideration of abstract philosophy - a body that can be left to look after itself while thought pursues a serene and absent-minded way. But how different when our bodies are too much with us; when each day is a new battle for survival in a relatively hostile world; when not for more than a few dreamy moments can the demands and deficiencies of the body be ignored-when even the luxury of at last feeling safe in bed is disturbed by demands which obstruct dreamless rest.

Where, then, to begin? My only certainties are that I exist, and that apart from the world of people experienced through the senses I would have no referents for knowing that I exist. In this, I am not set apart from others. My concerns are their concerns, though because disability

tends to accelerate the natural processes of passing time, mine are more immediate. We cannot ignore the risks and dangers until too late. Things just possible yesterday become just impossible today. It is preferable to face these things now with maximum conscious awareness than to be unpleasantly surprised by them later. Perhaps!

Nevertheless, why has providence, I may ask, chosen me for this special treatment? This is a question we must all have posed at some time. It is a dangerous question to which there is no certain answer, though many quasi-religious explanations have been suggested. Some sufferers have felt 'chosen' for special and unique personal qualities, which often leads to insufferable pride.

Others have felt themselves being punished for crimes they know they did not commit, which may produce a 'chip' on their shoulders, destroying contentment and creating much misery within the family. Both attitudes are distasteful to me.

What of organized religion? As a disabled agnostic who longed to be convinced, I sought. that I might find. Everywhere I was made most welcome until I asked my questions. The replies were only for the already converted. Yet they meant so well, these people who were relieved to see me go. Other great religions stood beyond Christianity, all so obviously rich with eternal truth. But one and all were choked with the varied interpretations of the centuries. The sacred cows were diseased, and flies fed on the leprous stumps: purest fatalism merged with mistaken confidence that here and now was not important. I came out by the same door as I went in.

Thus came ultimate disillusionment. Utterly alone and deserted, it did not matter to me that others cheerfully bore heavier crosses. In this spiritual wilderness all was so

black, blank and formless, so devoid of point of reference, that neither picture nor memory can recreate it. Then providentially a new person emerged under some compulsion outside myself. The sensation of peace after storm has come to many, disabled or not-the experience of having passed the point of prayer to whatever gods one has dreamed of, and miraculously survived the ordeal. It is a metamorphosis, a sort of rebirth-one of many such, but the first and therefore the most important. The new person is strengthened, enriched, more content, and yet contains all the old sorrows. From then on, disability becomes incidental to life, and progressive limitations are successive hurdles to be not so much overcome as circumvented and made innocuous. It is a great loss to be denied access to the high hills, the feel of springy turf. But the breadth of the known and unknown universe spread before one's feet makes it no longer destructively shattering. How the vast cosmos arose, or its creator came to be, becomes a secondary consideration to the inner certainty that life is essentially good and worthwhile-that one's own trivial life is an integral and necessary part of the completeness of things. These thoughts have been written and voiced through the ages, and are not very original. Only philosophers and theologians have sought to explain self-evident truths: for the rest, it has been enough that-practised faithfully-they have proved effective and relevant to life. When a thing has worked sufficiently often, however inexplicably, and when one has experienced it oneself, one inclines to believe it. With new perception, and the world a footstool, the results are beyond doubt good-good, good for me, good for all; and far from blind faith.

It is a continuously uphill task for the disabled to achieve and maintain inner serenity. Admittedly, added limitations enhance the eventual value of achievement, and life

becomes an empty affair when divorced from some sort of spiritual goal. But every-day difficulties have an immense power to irritate, frustrate, embarrass, and exaggerate the loss of independent action. And the amount of the deficiency, the area of its influence, will decide what practical steps are needed to be effective.

Regardless of our condition, we are all members of society. As such, we have social needs and social obligations. We cannot successfully live in isolation from the community, and must strike a fair balance between these two aspects. As disabled persons, we may find this extremely difficult unless the remainder of society makes certain initial concessions to help us to help ourselves. And of all the help society can offer, employment of some kind is the most important, as a key to adequate finances to free our families and ourselves from the fear of undue hardship. We all wish to be useful-to earn our keep. There is an undoubted therapeutic value in work. We do not mind aids or subsidies; 'but we draw the line at total support in idleness. We can make a social contribution. We dare not take things for granted, and-given an opportunity-can set an excellent example to our fellows. A report from the United States Congress after the war showed (I quote from a recent article by the Speaker of the House of Representatives) 'that handicapped workers equaled or bettered non-handicapped workers in productivity, punctuality, safety and job-holding ability'. This, without doubt, is of universal validity. Since suitable work is rare, we do not risk our position, and will reward a helpful employer by our diligence.

My experience persuades me that the Disabled Persons Employment Act has failed to help all but the least seriously disabled. And such organizations as Remploy cater for isolated pockets, only touching the fringe of the

need. Further, I am convinced that Disablement Resettlement Officers are hamstrung by the lack of employers who will make special provision for additional disabled workers. In twenty years, I have had not one iota of useful advice or help from either. Quoting again from the same source as above, which itself quotes President Johnson, in a directive to the Administration: 'Your full co-operation is needed to make sure that all persons concerned with hiring, assignment, and use of employees. ..constantly examine the work to be done and apply imagination. and ingenuity to re- engineering jobs; to retraining employees; to finding less demanding assignments for those who become ill or injured, when this is necessary for their continued employment; to dealing with the handicapped on the basis of ability and fairplay.'

I reiterate the value of work, preferably creative, for the disabled. The fit may perform soul-destroying tasks, and then for relaxation escape into the wider world. But for us, work is itself leisure and pleasure-often there is no escape, and to work is the only way for us to feel useful to and needed by the society in which we live. That is why I emphasize the words of President Johnson, stressing the great care required to assess and provide an appropriate occupation for the individual disabled person.

There is a scale of degrees of disablement. The least unfortunate can be fitted into existing occupations with a little adaptation. With transport available, this group is increased. The next group can work in sheltered, adapted, and possibly subsidised conditions. Another group could perform craft occupations in their homes (perhaps initiated by occupational therapists). This presupposes a market for the products, and a marketing organization similar to that of the old cottage industries. Finally, we must think of the paralysed, dependent on others for mere survival. I refuse to believe it is beyond human ingenuity and

understanding to enable them to make some social contribution. But I cannot pretend to solve their problem.

Amongst the various charitable organizations there exists a chaos of overlapping activities. There is surely a strong case for increased co-ordination and co-operation with State agencies, which would mean greater achievement for the same communal effort. Such is the confusion that many disabled people are uninformed of the possibilities for guidance and help. My own awareness of existing facilities (for which I have unbounded gratitude) is the fruit of years of patient exploration.

In the immediate post-war period I might have remained unemployed, but for the timely intervention of individuals and much personal persistence. Much more recently I had to seek an alternative position after thirteen years service, partly owing to physical deterioration. I dread to think how many, lacking my persistence, have retired from the unequal battle.

This present job of mine, however, would not have materialized without a personal means of transport. The provision of aids is a field in which I think Britain really does lead. But there is also no doubt that modern technology, even without advance, could do much more to mitigate disablement if it simply reached all those in need - which it does not. Prices of appliances are frightening, especially those for the more seriously disabled. Yet these things can lighten the burden on the sufferer and his family. Oddly enough, the price of a special appliance caused me to contact the Ministry of Health, who provided one readily. An instance of poor public relations?

Each disabled person must decide how far to concede loss of independence, and how far there remains the power and urgency to combat its effects. Partial isolation

through inability to take part in many leisure activities has a certain perverse merit-it compels us to have more exacting standards, and to value our more reliable friends. Real friends are in any case rare though an extrovert life may disguise the fact. We do at least learn the truth, even if it hurts. We have to learn that some outside help is essential. When it comes abundantly beyond our need, the hardest lesson to learn is to accept it bravely, with genuine gratitude. Too much help weakens; but the ingenuous spontaneity of the small, even unnecessary, service can bring perennial delight. When our fight becomes intensely personal where self-help is the only way-we must learn to live a full and adapted life within our limitations, even in the face of a hostile environment. There is no specific virtue in disablement; but neither is there any particular evil, except thinking makes it so. Yet, seen in proper perspective, it brings cathartic benefits.

The field of disability is demonstrably world-wide, though it has been considered in a rather insular and parochial setting. We must remember the effects of widespread malnutrition and endemic disease in underdeveloped countries. Against this back-cloth, we who suffer in a more highly developed and sophisticated society should attempt to view ourselves. We must hope to see uniformity of treatment for the disabled not just in Britain, but throughout the world.

And where does disability end? The widow with children, the coloured man, the ex-convict - these too are socially disabled: and all are potentially disabled. At some time, everyone will need a Good Samaritan.

Several things emerge. Our special contribution comes from an increased awareness of the transitory nature of life; the ever present dangers of existence are for us in bold relief. There is need amongst the disabled for

communication with others; real communication. Even we who know disablement from the inside cannot be sure we know how another person feels. The identical limitation can be far worse for one person than for another. It is important for the disabled to be accepted within society; because the actual impact of disability is linked with the loss of facility for complete social integration.

Another pressing need is for an integrated and well-published general policy, where the disabled know to what they are entitled by reason of disablement, and know that this is the wish of the community. I am sure that the initiative for this must come from the disabled themselves.

Disablement need not, must not, sound the death-knell of all ambition. There are small everyday embarrassments which make essential privacy impossible and to which we never quite become reconciled; and there is enforced solitude when we most need company. But our concern is to achieve spiritual fulfilment more or less in isolation. Many bear witness that it can be done, though others show it need not be. From those having different disabilities one often hears: 'But I couldn't endure what you have to put up with.' The fact is, of course, that one adapts or one succumbs.