

## **Audrey Shepherd**

Audrey Shepherd, born in 1927, was educated at Leeds Girls High School and Bingley Teachers Training College. She taught for some years in Leeds before taking a post in Nigeria.

Getting polio at the age of thirty, she spent a year at Pinderfields Hospital in Yorkshire, which she says it is impossible to praise too highly, but which left her with a marked aversion to all forms of handicrafts.

Miss Shepherd is now teaching at a secondary modern school in South Leeds. She is a local preacher in the Methodist Church, a pacifist, and a left-wing member of the Labour party. She lists her hobbies as reading, talking, sleeping and visiting the Yorkshire lakes.

### **One Body**

**(Chapter 5 in Hunt, P. (ed.) 1966: *Stigma: The Experience of Disability*, London: Geoffrey Chapman).**

'THERE ARE two ways of dealing with adversity. One way, the easier, is to ignore it altogether. I have got about as far as that. The other and more difficult way is to face up to it and triumph over it. I can't manage that yet, but I must learn to do it, for the first way is really a slight though, I believe, permissible piece of self-deception.'

Those words were written by Dietrich Bonhoeffer, a German theologian and pastor, imprisoned by the Nazis in April 1943, because of his opposition to Hitler's regime, and put to death by them shortly before the end of the war. Letters which he wrote whilst in prison, and smuggled

out to his parents and friends were collected together after the war and published.<sup>1</sup>

Much of Bonhoeffer's thinking has in recent years helped me to come to terms with my own life; therefore this seems a good place to begin. Possibly the most difficult thing for any disabled person to accept, especially if the disability comes suddenly, severing past life from present with one ruthless stroke, is that the incredible has actually happened. This leaden, partially paralysed body with which polio has left me is mine, and belongs to the same 'me' who hitherto walked and cycled, swam and played games, travelled on buses and scrubbed floors. It may be a platitude to say that acceptance of this is the beginning of any real recovery as an integrated person yet platitude or not, it remains true.

But what does this acceptance mean? How does it actually work out in daily living? Clearly it means different things for different people. Bonhoeffer's words indicate what it means for me, which is why I cannot accept the philosophy running through some books written by the disabled, much as I admire the courage and determination of the authors. If I understand them correctly, their line of thought is something like this: 'Disability has made very little difference. I can still be independent and do all the things I really want to do. What I wish to achieve, I shall achieve.' Titles like, 'I Walk On Wheels', indicate this. There is here an ignoring of adversity which is heart warming in its cheerful gallantry; but it is not the way for me.

Because I don't walk on wheels. Either I ride in a wheelchair, or stagger along, with a strange gait, on crutches. There are those who would say that this sort of recognition paves the way to self-pity, that most corroding

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<sup>1</sup> Letters and Papers from Prison, Collins, Fontana Books, London, 1959

of attitudes. There may be a danger of this, but one can only live with oneself on certain terms. In his prison cell, Bonhoeffer saw very clearly that for some things there are no substitutes, and this is another insight of his which I have found invaluable. It was here that I found a new beginning which made sense, which neither denied the past nor made a mockery of the present, and which made the future hopeful. There is no substitute for walking.

A ride in a car is a pleasure, but not a substitute for walking over lonely moorlands, with the heather springy under the feet and the sky blue overhead. Diving, racing into the sea, dancing and climbing hills - these were all good and there are no substitutes for them. But I cannot pretend that they have never been, or that I did not find great joy in them, just because they are now no longer possible. Walking is far more than a means of getting from one place to another, and I cannot be false to the earlier part of my life by pretending otherwise. Acceptance means the facing of this sort of reality; it means allowing the knowledge that for some things there are no substitutes to sink into the depths of the mind, below the rippling surface of the conscious; and this means patience and a willingness to wait. If I seem to have made rather heavy weather of this, it is because the life built up, bit by bit, after the onset of disability will be built on the foundation of acceptance. The beginnings will depend on the content we give to that word, and the beginnings will, to some extent, define the ends.

If energy is limited, the next step will be to give some thought to priorities. Whilst still in hospital, I decided that if it were at all possible I would walk again, not necessarily well or far, but a little, and that year by year I would extend the area in which I did not need to use a wheelchair. That was over six years ago, and for a long time it seemed that the nature of the paralysis would make this impossible. At

first I needed two calipers, but was never able to move the right leg, as the 'hitching' muscles necessary to swing through a stiff, calipered leg were not working at the right side. Another problem was the fact that the left arm was completely paralyzed and therefore I could not hold an elbow crutch. The latter difficulty was solved by an inventive physiotherapist who designed a special crutch. This I still use, and without it the walking project would have been impossible. Eventually, too, it was found possible to brace back the right knee without a caliper, and then to flick through from the hip. At first I could only walk a few steps, but gradually the distance has increased, and further progress has been made possible since muscle transplanting operation last summer.

Each January, I have made a list of things I hoped to be able to accomplish before the end of the year. At first, simple, everyday tasks such as dressing and undressing, getting into and out of bed featured on this list, and for a long time getting up from a chair proved to be a stubborn obstacle-though not flopping down into it!

Slowly, however, the original goal is being reached. Now I can manage without a wheelchair in the house and garden, and almost entirely at school. Perhaps in another three or four years' time I shall be able to do without a chair altogether. This rather lengthy illustration I have used because it seems to highlight several points. Firstly, the fixing of priorities. Walking was one of mine, and because it was, other things have had to wait or be left on one side altogether. Other people with different temperaments or in other circumstances, will have different priorities. What matters is that our aims, whatever they are, and however difficult they may be of fulfillment, are not completely beyond the bounds of possibility. I think we have to recognize our limitations, and then set our aims within these limitations and work

steadily to accomplish them, even if it takes us years to do so. But because we are human and therefore need encouragement, it can be a help to have 'aims within aims', more immediate goals which can be reached on the way to the final goal.

There is always much talk of will power in connection with disability, perhaps too much talk. When a disabled person has achieved the seemingly impossible, is it will power or is it 'want. ting' to do something? Both perhaps? But you have to want first; whether it is to go abroad, get a job, drive a car, become proficient at archery or swimming, or do anything at all except sit and gaze at the holes in the carpet. It's not true, of course, that if we want to do a thing enough we can do it. Always the phrase, 'within certain limits' must be added. But it is true that if we want to do anything enough, the limits may be extended beyond our imagining. For this is where will power comes in; to understand and sustain us when we start to put our visionary 'wanting' into practice.

After the beginnings, the settling down. After the year in hospital trying to learn the meaning of acceptance and to sort out priorities, came the return home and the resumption of life in the world outside the comforting hospital walls. I was one of the fortunate ones, able to go back to the work I had been trained to do, teaching, at first part time, then, after a year, full time. Now I am teaching in a girls' secondary modern school, mostly the thirteen to fifteen year olds. Teaching can be done relatively easily from a wheelchair or on crutches. The children, after their initial interest and curiosity, return to their age-old pursuits - listening or working in a desultory fashion, trying to get away with passing notes, chewing or knitting under the desk. They become neither angels of light nor devils incarnate, but as far as I can see, behave now in much the same way as they always have behaved. This, especially

at first, I found a great tonic. To be with children who are more interested in their own pursuits than in me, and I to be able to do a job of work, these are great sources of healing.

In the same way, to be with my colleagues on the staff is therapeutic. We talk politics, school affairs, books, religion. Disability is forgotten as I am received by them as a normal person, interested in many things. Much of my present happiness I owe to them, and to the head mistress who took the risk of accepting me on to the staff. I have never been allowed to feel a passenger, even though others have tactfully carried various extraneous duties, such as dinner and break duties, for me. The rest of the staff have made a joke of any assistance they have given me, helped me with sympathy and humour, and offered me a place on equal terms in a community. It is difficult to explain how much these things mean, but our longing to have a real place in society again indicates that we are not meant to live as isolated beings.

What the answer is when one is quite unable to take a job again, I don't know. Only those who have lived through that situation can tell us that, but I am sure if it is humanly possible to get back to work, it is worth almost any sacrifice to do so. There may be a price to pay. For me, part of the price has been fairly constant fatigue, so that I often have to spend long periods doing little but going to school and coming home to bed. This is annoying, of course, especially when there are many things one would like to be doing during the evenings, but a job is cheap at that price.

Independence is generally thought of as being of great importance, but how important is it? Are any of us independent anyway? Are we not rather all interdependent? Of course, it is worth trying, if it is at all

possible, to be independent in the everyday things of life-washing, dressing, getting about the house, etc. When the disability in question is the paralysis following polio, often the years bring increasing independence, as one is able to work out new ways of doing things. But I think too much emphasis on independence can breed fanaticism. If I am in the wheelchair at school, it bothers me not at all if somebody pushes it along for a bit, making a joke of having something to lean on. Why not? Yet I have known those who go tense with rage and are quite rude if any help is proffered.

This seems to me to be getting things out of proportion. The able-bodied are helped by their friends and help them in all sorts of ways. Why do we want to put ourselves outside this mutual help by which society exists, and insist on self-help? Perhaps partly because we have felt so helpless in hospital, reduced in the early stages of disability to a childish dependence on nurses for everything: now nobody is to help us in any way. But this is artificial. To follow it through to its logical conclusion we should have to contract out of society completely.

We seem to come back to priorities once more. If any measure of independence, beyond independence in everyday things, is really important to one, a real 'want', then it is worth while going all out for it. If it matters to me to live in a bungalow on my own, to do all my own cooking and cleaning, or to travel about the country alone, then that is worth striving for. If it doesn't really matter, if it is only a theory that it is good to be independent, then it is not worth working for. This, I am well aware, will be considered sacrilege by many!

Aids to independence, however useful, do not come very high on my list of priorities. For me, the two most important things in the whole process of rehabilitation have proved

to be a job and friendship. The former I have talked about at length, but the latter is of equal importance. I have been richly blessed with a loving, imaginative and understanding family and with many wonderful friends. What I should have done without them I cannot imagine. It is because their help, interest and ideas have so helped me along the road towards independence, that to make a god of independence seems ludicrous.

I have had many days with friends in the beautiful Yorkshire dales, entertaining and being entertained; and spent holidays with friends, never ceasing to be amazed at the trouble they are prepared to take to make the holiday possible in the first place, and very enjoyable in the second place. All these are things which bring great joy.

I suppose increased mobility is the factor which most easily distinguishes the life of the disabled today from the sort of life lived by the physically handicapped earlier in the century, and I have had reason to be grateful to the firm which produced a wheelchair with a right arm control. With a little practice it is quite simple to steer and control the chair completely with one hand. Recently my mobility has been further increased as I now have an electrically-propelled vehicle, which is very useful, especially for travelling to and from school. Acquiring and learning to use these things are all a part of the settling down process, which may take a period of several years; but after that, what? When a job has been found and anything that may be of practical help has been made use of, what then?

Then I think we have to learn to take a place in society again and I believe the answer here lies in integration, rather than segregation. By segregation, I mean all those things that tend to cut off the disabled from the rest of

society, and make of them a distinctive group-clubs for the disabled, magazines for and by the disabled, schools for physically handicapped children, etc. If our comprehensive schools really were comprehensive, it should be quite possible for them to accommodate disabled children, instead of sending them to separate schools and by that very act cutting them off from the rest of the children in the street. There would be problems, of course, but certainly not insuperable ones. For instance, it would be quite possible for a child in a wheelchair to attend the school where I teach, and the benefit to the child of going to the same school as her contemporaries would, I judge, be enormous.

In the same way, are clubs for the disabled, or even for those with one particular disability, really a good idea? The British Polio Fellowship would say that they are, and I have been challenged on this point by a young woman, very severely paralysed, who is unable to go out to work. She had no doubt that her life would be much duller and emptier were it not for the local branch of the B.P.F., and I am sure she would be echoed by thousands of people, completely house-bound apart from the 'club' and the club's activities. All this I can see and understand, as I can appreciate all the voluntary work which goes into the life of such clubs. But is it really a good thing to draw into one place and link together in fellowship those whose bond is their disability? I think our society would be a happier and healthier one if youth clubs, Church groups, townswomen's guilds and the like were to make a determined and deliberate effort to draw handicapped people into their midst, instead of encouraging them to meet in 'separatist' groups.

Part of the trouble is that in England today there is an almost total lack of real community life. We have little sense of being bound in one body, a body made up, not

only of the healthy and the prosperous, the respectable and the successful but also of the old, the failures, the mentally ill, criminals, the physically handicapped, the emotionally crippled, the misfits, the awkward squad. Because of this, but also because society has a 'conscience' about its less fortunate members, it preserves its respectability by pursuing a policy of apartheid. And so there grows up a community without a heart. The 'norm' is the man with a house, family, garden, job and a car at the gate. All the misfits are divided into their respective organizations. They have been catered for. A great deal of money has been spent on them and that should be enough. But it isn't. Instead of a community bound together by love and tears, rejoicing and suffering, we are left with a closed shop, an exclusive club, lacking life because it lacks wholeness.

This is the picture I see as I look at our society today; it is obviously unfair to put all the blame for this segregationist policy on to the rest of society, though I think they must carry their share of it. What of the disabled person? Does he want to be come a part of the community, and not just a section of that community, and if so on what terms? Most of the emphasis in our hospitals today seems to be placed on delivering people, who are in some way mentally and physically hurt, from their early moods of self-pity, despair, rebellion, bitterness or self-centredness. Obviously this is good, but the danger lies in following this by giving the people concerned an inadequate goal to work for. In most occupational therapy training for instance, the emphasis is on independence and, as I stressed earlier, I think this is insufficient- a necessary pan of growing back to wholeness, but only a pan. Surely, the emphasis is wrong. It can never be a question of going back to the old life, in spite of what has happened, but of going forward into a new life because of what has happened. Now the disabled person offers himself to the

community in a different way, because he has new limitations but also because he has new insights. The community is helped to remain whole, for the strength and tenderness of the able-bodied members are needed. The disabled one is also helped. He is lifted from self-centredness into the life of the whole community. The tragedy is that this is made very difficult when the community is divided into clubs of like-minded people, or of people in a particular situation, instead of people taking their places fully in society, accepting from others and giving to them.

One of the real difficulties which prevents the disabled person from believing that he can really take his place again in the life of the community is that we have grown up, in this generation, with a great belief in the value of endless activity. So often, there is the sneaking fear that if a man cannot rush from job to job and fill every minute of the day with bustle and vigour, he cannot really be a useful member of society. The belief that it is better to do badly something active, rather than something more contemplative well, is almost universally accepted in Western Europe, if not in Asia.

All this makes it more difficult for the man who has led a very active life, and is now limited in some way, to know what to do. One must work for the community if one is to be a part of that community, but when, for years, work has been thought of in terms of bodily activity, the necessary adjustment to disability is not easy. It must begin with a glad acceptance of a new way of life, and hankerings after the old must be put away. Once there is this acceptance, then the way opens up and there is much work of real value which can be done. It must be work of real value, not just something to 'help pass the time', or it will lead to a deeper sense of frustration and helplessness. This work may include letter writing, conversation, study, for some

meditation and prayers of intercession, and for others the making of objects of real beauty. In this machine age there is a real need for the craftsman.

Finally, since I call myself a Christian, I am faced with a question. Does my personal faith make any difference to my attitude to disability? It is difficult to say, for whilst I would contend that my whole response to this particular situation stems from my Christian faith, a humanist, working from different tenets, might well reach the same conclusions. I believe that an important part of being made whole involves learning to absorb suffering instead of passing it on in another form. I am confident that it will take me the whole of my life to learn how to do this one thing. Suffering comes to us in the forms of pain, frustration, ill health or unhappiness, and we take our part in the vicious circle of never-ending suffering by passing it on to other people in the forms of irritability, resentment, bitterness or cynicism. But hope for mankind will only come when we cease to do this, when 'we absorb the suffering that comes our way and render it powerless by our refusal to pass it on to other people in some other guise.

Seen in this light, suffering is robbed of its most unbearable feature, the sense that it is futile and meaningless. It is seen instead as a challenge, not in a pious but in quite a practical way. To say that suffering no longer meaningless is not to say that it ceases to be inexplicable. It remains, or much of it remains, mystery.

For me, disability means learning to live a double life! At the same time as accepting my present limitations and seeking to take a new place in the community, I must work with God for wholeness, and this is done secretly, in the heart. 'Trying' and 'fighting' can make a person hard, determined to accept help from nobody, cold and

arrogant. The paradox is that nevertheless one must 'try' and 'fight', quietly, faithfully, gently and patiently. For the Christian this means. that the trying is done 'in the strength of Jesus, plodding along in his steps, for it is the Father's will that have should be made whole, as individuals and as a community.