

Childhood

Is Something Precious 1948

It is a hard never-ending fight – which no cerebral palsied child can ever evade. The struggle is entirely personal – no other person can share it – doctors, teachers, therapists and parents can encourage and direct the child. They can arm and equip him for the struggle – but he must still fight out the lonely battle on a ground that is beyond their reach. Whether the terrain favours him or not depends entirely upon the equipment and organisation with which we have endowed him.

In 1947, we produced an illustrated colour brochure outlining our policy; forty years later I would have difficulty in faulting it:

'Contact with childhood gives us all an opportunity of renewing ourselves, or slipping off for the moment our mundane cares and worries and enjoying its clean simplicity. Children should be happy – they are not born to tragedy – there is time enough for that in later years. But what of children like ours who, through no fault of their own, are denied their birthright – bound from the very day they are born; are they to be left in their dungeon of frustration and despair because it costs a high ransom to strike off their bonds? Or are they too, to be released to enjoy the sunshine and the happy shouting of the playground?

It can be done – it is being done here at The Centre every day, but it has a price – a price which is largely paid by the child in long years of unremitting training, treatment and of schooling under conditions which might at first seem impossible. You and I must contribute the price – we must see that the tools are available for their work, and that means – money!

These children have had damage too, or failure of, development of those parts of the brain which direct and control voluntary movement and posture. Anything which causes damage to these areas can produce the condition. Sometimes cerebral palsy is associated with hearing, vision, speech or mental defect.

Damage usually occurs in relation to birth. Most frequently, it is the first child of a family. First births are usually the most difficult. A long labour, a tired mother, a difficult delivery may cause cerebral haemorrhage and thus brain damage. A badly shocked baby does not breathe well and so does not take in an adequate amount of oxygen. This lack of oxygen may itself cause damage to brain cells.

Extreme prematurity is a frequent cause. The very premature baby is susceptible to spontaneous small haemorrhage into the brain tissue and so brain damage. A too quick or precipitate birth may bring about a tearing of the membranes which cover the brain and cause bleeding into the brain tissue.

Recently it has been shown that cerebral damage can occur in association with heavy jaundice of the newborn, due to the Rh

factor and parental incompatibility. Sometimes the condition is acquired after birth through accident or disease such as encephalitis or meningitis, perhaps following measles.

Education and treatment are absolutely essential. Even though they must forego their rightful heritage of carefree childhood, for a spartan training that is beyond the conception of a normal happy child, they are entitled to training and education – they must be given that chance!

The work accomplished by the children in the schoolroom is the final test of the value of our intensive medical and physical treatment and training. It is of little use improving the function of a twisted wrist, if the hand is not then taught to write. It is of little value teaching a child to walk if he is denied an education that will give his walking a purpose. We are very satisfied with the school standard attained by our children in spite of their handicaps.

Reg is using the electric typewriter - he could not read or turn his pages three years ago. Betty, despite her lack of effective speech and difficult hand control, has learned to read and use an adding machine. Despite her poor speech and hand function, June wrote the play for this year's school concert, and has had several of her stories used by radio stations.

These children are clearly on their way – the way is long, hard and exacting, but we are erecting some signposts where we can, and ask that you, too, stand by to give them some aid over the steeper parts of their climb. They can make the grade – they must not be denied the chance. They're worth it.

These eight infant class children are widely different; they have different handicaps, different teaching problems, different potentialities. Their physical handicaps vary from Kerry, who is still unable to walk but whose speech is good, to Stafford, with athetoid movements which are involuntary and sometimes only partially controlled, who works so well and whose speech is so affected to be almost absent.

But they all share one very, very important characteristic – they will face up to any task allotted to them with an intensity of purpose which disregards bodily discomfort and a succession of continual failures until they finally master it.

Can you imagine just what this work means to the individual small personalities whose handicaps have cut them off from so much, often from normal life experiences such as simple learning? Can you imagine Stafford, minus speech, learning his letter by nodding 'yes' or 'no' to his teacher as she places the matching cards in front of him? The time-consuming repetition until he progresses to words, then the slow building of an unspoken vocabulary, the misspelt words on the blackboard, and the flash that illuminates his whole face when the pointer moves over the correct answer? Then for the teacher, equally with Stafford, the quiet bubbling pride in watching him ultimately read from a book.

All of these children have similar stories. Julie is as proud as a peacock of a blue bruise and lump on her forehead, because yesterday, for the first time, she walked three unsupported steps. She fell, but to her the bruise is an accolade.

Beverley last week walked alone for the first time in her life, on rough skis made by her father. She was not satisfied with a three or four yard essay, but insisted on teetering and wavering the whole length of the hall, and then repeating it for good measure without falling once. She has hardly stopped walking since. Her hands are not yet sufficiently improved to hold a pencil, so Beverley is busily spelling out the answers to the blackboard exercises by arranging her letter blocks, but she is expected to start writing very soon now.

Kerry is the popular girl of the class. She can walk and talk, and mothers the others with a comical seriousness. She is writing what Julie dictates, because she must have somebody to turn her pages and write down her answers.

Jennifer, who is still unable to hold her head erect, uses a ballpoint pen because she must support herself by her hands, and a pencil point would break.

Graham started walking the same week as Beverley. This is not a sudden achievement, but is the culmination of more than three years of intensive training, associated with the stimulus of the recent visit of Dr Carlson, which immediately inspired many of our older children to increased effort and confidence.

If, with our unimpaired bodies, you and I could attack the problems of our relatively uncomplicated lives with the fixity of purpose and concentration of these children, who knows to what heights of endeavor we might not aspire?

We are proud of our Nursery children. Whenever our parents or staff members permit themselves the luxury of a fit of the blues, there is a certain cure ready at hand in ten minutes observation of this interesting little group. Completely unselfconscious, reliant and brimful of vigour, they are a sheer delight to watch. Their activities are based upon free play and group activities, controlled in accordance with the individual child's muscle training programme, and their progress is faster and more certain than any other age group. It has been found possible to obtain effective co-operation, even from some babies as young as ten months, and this augurs well for the future preventive work which should be done for every such child.

There is Tim, who has his centres of balance and position impaired. For three years, from the age of sixteen months, Tim has been taught never to relax his attention from what he is doing. Should his attention stray he folds up, and must then hoist himself laboriously to his feet again. The time between falls is gradually being extended, and some day soon he will go through the day without a fall. There is absolute certainty in his future ability to win out in the way in which he accepts the fall and immediately gets to his feet again. He has never stayed down. It would be so easy for him to just give up, but he has never stayed down yet and he never will.

That is why we can never slacken off in our self-imposed task of doing what needs to be done for these babies. With early training they will release themselves from the tyranny of crutches and invalid chairs – without training many are inevitably doomed – we can never give up while they are still prepared to fight on.

To walk – two poignant words that carry such a wealth of magical meaning to a child who cannot move from his chair. If you have spent a few weeks in a hospital bed you will remember the frustration of waiting for a nurse to enter your room. Do you remember the eagerness with which you looked forward to being able to take yourself to the bathroom, or the daydreams in which you tasted the future bliss of just being able to walk unhampered in the sunshine down to the corner of the street? It is heartbreaking to watch the effort some of these boys and girls have to put into the simplest movement – but the underlying sadness of the children's personal tragedies assumes a different quality for those in close touch with their work because of the constant drama of achievement presented. For months, sometimes years, a child will appear to make little physical progress, and then suddenly he commences a spurt. Every success then spurs him on to greater effort, and often a surprising gain is made before he again settles down to a steadier pace.

You can readily imagine the pride and radiance shining from the face of an eight-year-old who, for the first time in his life, stands alone, wobbling against a wall pad or tensely swaying on walking skis. In learning to walk, aids of many different kinds are used. Dawn uses the skis to obtain stability – for her it is a hard uphill climb, but her eyes are on the difficult peaks she must still surmount before she, too, can join the joyous laughter of the children at play. These are the occasions that make a song in our hearts and all the effort worthwhile.

The cerebral palsied, despite the severity of their physical handicaps, must be treated as normal children first and foremost. Their handicaps are incidental only to their needs as a normal child and do not take precedence over them. Only too often treatment facilities are focused entirely upon the alleviation of the child's disability and his needs as a normal child are completely overlooked.

It is little use curing a crippled leg if the process involves crippling the child's mind by denying it the opportunity of developing along normal lines. Education is necessary for all, but it is of absolute importance to the cerebral palsied, whose limbs will always be affected to some extent and who must, therefore, discipline himself by physical and mental training in such a way that he is able to compensate for, and rise above, his deficiencies if he is to successfully adjust himself to normal society. There must be no sentimental half measures involved. A handicapped child can seek and obtain all the emotional sympathy and help that he requires. As an adult he must, in social and economic competition, match up to normal people, irrespective of his disability. He is entitled to assume that his handicap will not be held against him, but he is not entitled to demand that the world gives him special consideration because of it.

The provision of proper plasters, braces and splints, immediately they are needed, is essential to prevent or control deformity otherwise inevitable. We believe that these orthopaedic aids are every child's right.

Can you imagine the eagerness with which the children await their school bus, their distress if it is late, and the speculation if it is diverted for a new passenger? They are not ambulances for sick children, but school buses for healthy but heavily handicapped children. To some the bus represents release from the monotony of a chair in a living room; to all, an interesting, exciting, new world of constructive work and play. New sums today, speech therapy tomorrow, companionship always. Travelling with their schoolmates and achieving for the first time in their lives, a special friend with whom to exchange confidences and special secrets. It is all thrilling, and very, very necessary.

You have seen our Spastic Centre buses, crowded with children in your suburb. In centres as far apart as Hornsby and Hurstville, Mona Vale and Maroubra, Revesby or Parramatta. Every week they travel a distance equivalent to a trip across Australia to Perth and back again. Purchased in poor condition from army disposals as ambulances, they were rebuilt as buses, with special seats to support the more helpless children. Every morning they pick up nearly one hundred children at their homes and return them in the late afternoon. They are our lifeline, without which we cannot function. Our children cannot use public transport and a residential treatment centre is not practicable.

It is not desirable that The Centre should be converted into a residential treatment unit, as this would reduce the numbers of our children to one-quarter, without in any way increasing the efficiency or reducing the costs of the schooling and medical treatment provided. The spastic child, equally with the non-handicapped child, needs the essential stability of a family home, brothers and sisters, relations and friends. We are, however, becoming increasingly disturbed by the plight of the many cerebral palsied country children who are unable to obtain training in any existing hospital or home, and of the difficulties of similar city children during periods when their parents are unable to properly care for them, owing to sickness or other domestic emergency. Think of the tragedy of seeing child after child, capable of benefiting from urgently needed treatment, which cannot be provided because their homes are in the country.

Despite the smallness of our organisation and our lack of funds, buildings and equipment for the purpose, we feel compelled to immediately organise facilities for the residential care of these children on a hostel basis. For the present, the children will be transported daily to The Centre for schooling and treatment. Later, it may be found advisable to add class and medical treatment rooms to the hostel.

All services provided for the children will continue to be free of charge, but parents will be expected to share their portion of the work and expense involved upon a co-operative self-help basis. A small permanent staff will be engaged, but the bulk of the work will be done voluntarily by mothers, their friends and by voluntary helpers.

Here is the simple story of a group of children in search of happiness

The development of the scheme is completely dependent upon securing suitable premises, but it is planned to provide for ten urgent cases immediately and to increase the number to fifty children within two years. As most of the children will be drawn from country districts, it is confidently expected that country people, generally, will assume financial responsibility – it will be money well spent.

This is not a survey of the rapid growth of a new charitable institution, born out of the heartache and bitter impatience of parents unable to obtain treatment for their children. It does not tell of struggles against financial failure and official indifference, or of the difficulties in wartime and afterwards of finding premises, obtaining a well-qualified staff, organising a transport fleet, erecting and equipping a building in the midst of a severe housing shortage, and getting a large group of people of all classes, types and creeds to work efficiently together towards a common end. Such a story might be told, but interesting as it may be, it has no place in these pages, because the real story of The Spastic Centre is the story of its children

Here is the simple story of a group of children in search of happiness. A group of quite ordinary boys and girls, fat babies, little pre-schoolers, school children and adolescents – trapped, through no fault of their own or their parents, on a treadmill of physical disabilities, on which they must remain until the day they die.

On and on they must go, the severity of their handicap determining the effort demanded of them as, lurching and stumbling, they relentlessly drive their stiff muscles, trying to keep pace with the normal world about them. If they falter or fall they are carried remorselessly backwards, and if not aided to their feet in time they are inevitably doomed to the debris of the scrap heap.

Some children fight back hard and learn to match their qualities of courage and determination against the calls made upon them. By utter concentration over long years of training, they learn to minimise the disabilities with which they were brought into the world. Others, whose disabilities are less, or who work harder to overcome them, free themselves from the treadmill altogether, and join their normal contemporaries in competitive society.