Personal Paper

Practical help in multiple sclerosis

SHEILA MILWARD

Twenty six years ago I developed multiple sclerosis, and I have been fortunate in having available many pieces of equipment. All these have helped me to live as full a life as possible. At the start of disability a comfortable walking stick is essential. When I had to retire from general practice this was followed by a self propelling lightweight Zimmer wheelchair, which we bought. It was more comfortable and manoeuvrable than any available through the National Health Service. At this time swimming improved my muscle tone enormously, and I swam daily. For some years I used a three wheeled Batric chair for walks across relatively rough ground, as far as two to three miles daily.

When my arms became weak I progressed to a hand controlled electric wheelchair by Bec, which enabled me to go round our large Victorian house and round the garden. This is an excellent machine, compact and easy to control.

When I could no longer use my hands I sought the advice of the occupational therapy department at Farnham Park Rehabilitation Centre. They suggested a chin controlled model. A chair made by Vessa and obtained from E S Richens of Oxford was adapted to accommodate my particular needs. It is a multipurpose chair, with two large batteries enabling me to drive outside, and can also instantly be converted into a pushing chair. I have just had fitted an alternative control and now the chair can be driven by an attendant walking beside or behind it. This was made by Mr Stan Cross of CABB Electronics.

Thirteen years ago we were given, on permanent loan, an adapted Mini with a ramp, in which I travel for distances of up to 20 miles—for example, for trips to the theatre, shopping, going out to dinner, etc.

Harness, hoist, and control system

When I am outside I must use a harness, which is made by Posey of California. This is neat and comfortable. On the one occasion that it was not used I was thrown from the wheel chair, sustaining fractures of pelvis, femur, and knee. We also have an adapted car seat made by D G Hodge and Son. This rotates, is pulled out from the car, and I am then transferred by hand from wheelchair to car seat, which is finally returned to the car.

For my personal hygiene I first used a bidet. When I became chairbound we had a lavatory unit fitted made by Clos-O-Mat of Sale, Cheshire. This washes the perineum with hot, then cold, water which is followed by hot air cooling down. Later a shower unit was added, and I now have a commode chair that fits over the Clos-O-Mat, thence to the shower. The commode chair can be obtained from F J Payne Ltd of Oxford.

Since I was catheterised in 1977 I have used a Shephard Sporrán belt, which is both discreet and practical. Before our present strict catheter routine there were many severe urinary tract infections necessitating admission to hospital and causing flare ups of multiple sclerosis. The T121 drainage bags have a capacity of one litre, need not be changed night and morning, and are emptied with antiseptic and no touch precautions.

I have an electric hoist supplied by the Buckinghamshire social services, which is infinitely superior to a manual hoist, used some years ago, which had to be returned because of discomfort and its unwieldy nature.

The Possum Environmental Control System is marvellous. It gives me independent control of lights, radio, television, telephone; I also have an intercom, buzzer, and alarm. In addition, I have a Possum adapted IBM typewriter, which I work with chin movements. I also have an excellent page turning machine made by QED of Gosport, Hants. In my experience this is the best machine available.

It is entirely to my husband's credit that all these improvements have been possible. Without his patient research and medical knowledge I would have led an extremely different existence.

My attendant's comments

My husband, who is my attendant, has made the following comments.

The walking stick should be of the correct length and have a rubber ferrule and a straight handle. Wheelchairs for paralysed, ataxic people should not have vertical backrests and horizontal seats. These are dangerous and were partly responsible for Sheila's fall. To overcome this problem she bought a Newton chair, on the advice of the National Hospital, Queen Square. She also bought a Vessa chair, which has in addition adjustable recline. The only disadvantage is its enormous size, so that Sheila is a long way from the attendant at meals, etc.

A ripple cushion (Talley) and sheepskins are best for Sheila, who cannot change position at all. We find that the "skins" made of fleece with nylon backing are softest and wash and keep best. We also use sheepskin heelpads, and a sand bag, numerous cushions, and pillows. Exact positioning of the patient is vital. A sheepskin over a Kylie sheet (Nicholas) is an excellent combination on the bed. Any leak of urine goes straight through into the sheet, leaving the sheepskin almost dry.

The Automatic Restaleg leg rest for use with an ordinary armchair is in daily use, with a sheepskin and foot muff (Home Supplies (Wessex) Ltd, Ashford, Kent).

A Posey (or other efficient) harness is a must for anyone paralysed above the waist.

The Clos-O-Mat is excellent for hygiene, but the hot air does not quite dry the bottom, and the washing does not always quite clean it, so a little extra attention is needed.

The Wessex electric hoist and slings needed endless trial and patience by the wonderful staff at Mary Marlborough Lodge, but it is much easier and quicker for a lone attendant who can lift Sheila manually to do so. If two district nurses were handling Sheila no

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doubt they would use it to everyone's satisfaction, and this may eventually be the case.

For drinking we treasure some rigid angled plastic straws, no longer made by Portex. We also use Insulex and Thermos mugs. The former have good square handles and are very light, and the latter are good for propping against the shoulder in bed. Cantilever tables with a T shaped three wheeled base are easiest to position at any height or angle for eating, drinking, and reading.

The Possum IBM typewriter belongs to the Possum Users' Association (now called SEQUAL), a marvellous charity of disabled people for disabled people that we discovered late in life.

We have been fortunate to be able to afford many things not available through the NHS and social services, and particularly to have many devoted helpers.

Names and addresses of suppliers

Disabled Living Foundation, Kensington High Street, London W11.

Everest and Jennings Wheelchairs—Zimmer Orthopaedic, Princewood Road, Corby, Northants NN17 2DX. (Tel 05363 67661.)

Batric now Batricar Ltd, Griffin Mill, Thrupp, Stroud, Glos. (Tel 0453 882243.) (New four wheelers very efficient.)

BEC Mobility Ltd, 103 Stourbridge Road, Halesowen, West Midlands. (Tel 021 550 7326.)

Farnham Park Rehabilitation Centre, Farnham Royal, Slough, Berks. Director, Dr J G P Williams.

Mary Marlborough Lodge, Nuffield Orthopaedic Centre, Windmill Road, Headington, Oxford. Director, Dr G M Cochrane.

Vessa Ltd, Paper Mill Lane, Alton, Hants GU34 2PY.

E S Richens and Son, 2 Windmill Road, Headington, Oxford OX3 7BX.

CABE Electronics, 2 Anstey Close, Waddesdon, Aylesbury HP18 0NB.

Posey Nursing Aids, obtainable from Camp Ltd, Therapy Division, East Portway, Andover, Hants SP10 3NL.

D G Hodge and Son, Feathers Lane, Hythe End, Wraybury, Berks TW19 5AN.

Clos-O-Mat (Great Britain) Ltd, 2 Brooklands Road, Sale, Cheshire M33 3SS.

New Oxford commode and shower chair (manufactured by F J Payne Ltd, Stanton Harcourt Road, Eynsham, Oxford OX8 1HY), supplied by Chiltern Medical Developments Ltd, Chiltern House, Wedgewood Road, Bicester, Oxon OX6 7UL.

Shepherd Sporan Belt and T121 Drainage Bags supplied by EMS Medical Ltd, Unit 3, Stroud Industrial Estate, Stonedale Road, Oldends Lane, Stonehouse, Glos. (Bags, but not belt, obtainable on EC 10, NHS prescription form.)

Noxyflex, vials, Geistlich Sons Ltd, Chester.

Possum Controls Ltd, Middle Green Road, Langley, Slough, Berks.

SEQUAL, The coordinator, 27 Thames House, 140 Battersea Park Road, London SW11.

QED Ltd, 1 Prince Alfred Street, Gosport, Hants PO12 1QH.

Newton Aids Ltd, Unit 4, Dolphin Industrial Estate, Southampton Road, Salisbury SP1 2NB.

Talley Ripple Cushion from Talley Surgical Instruments Ltd, 47 Theobald Street, Boreham Wood, Herts.

Sheepskins, either Posey, as above, or Dermalex Company Ltd, 146-154 Kilburn High Road, London NW6 4JD.

Kylie Sheet from Nicholas Products Ltd, 225 Bath Road, Slough, Berks.

Following a persistent skin reaction to a silicone coated Foley Catheter, a Bardex all silicone catheter has been supplied by Bard Ltd, Pennywell Industrial Estate, Sunderland SR4 9EW. (Initial result promising.)

Most of these aids may be obtained from the National Health Service or social services, depending on local conditions, for patients in the United Kingdom.

MATERIA NON MEDICA

Meandering by bus

Turkey is a wondrous subcontinent, and travelling by bus is a good way to become acquainted with the country and its people. The mingling of old and new and east and west occasions frequent surprises and interest. A long journey in a Mercedes-Benz pullman is likely to pass quickly under the courteous control of a conductor who regularly sprinkles eau de Cologne on the outstretched hands of each passenger, distributes juicy cherries, and is ever willing to leap in response to requests from passengers for bottles of spring water, which are always available from a cooler in the rear.

Drivers are justly proud of their skills, which are apparently undiminished while chain smoking. They are also unpredictable in their choices of cassette, with the result that a Turkish microtonal vocal rendering may be followed by the theme tune from "Dynasty." Old traditions of helpfulness and consideration are preserved. On one occasion when three passengers were standing we stopped at a seemingly random wayside cafe, the conductor scooped up slatted wooden chairs from round a table these were then squeezed into the aisle, and we swished away.

There was an unusual distraction while we crossed the alluvial plain of the river Meander. In discussion with fellow passengers a young Englishman said he was a professional conjuror and magician. Though on his honeymoon, he consented to demonstrate some of his skills, to the delight of passengers at his end of the bus. A vanishing trick using his neighbour's bus ticket was particularly entertaining, although some of us were aware that the driver's gaze was concentrating too much on his rear view mirror in an effort to detect the performer's sleight of hand—the course of the bus was itself bearing a disconcerting resemblance to the Meander river.—DENIS GIBBS, physician, London.

Jog on, jog on the footpath way

As I trudged wearily along the Corniche of Al-Khobar, searing hot sand on the left, omnipresent Saudi construction on the right, I thought to myself, what would happen if I dropped out? Here I was, dead beat, dog tired, done out but determined to make the harbour and back. We mad "joggers" drag on like the proverbial Englishman in the midday sun. What if I was found disorientated, dehydrated, even dead, on the pavement? Who would know who I was? Another dead foreign body in the street. Anonymous, unknown, unlabelled, and unloved.

I recalled a conversation with a fellow plodder in another city, where he spoke of the problem of unidentifiable, speechless, collapsed, or conked

out joggers at international medical meetings. Should joggers in foreign places be compelled to wear "jog tags"? This would prevent their becoming unidentified foreign bodies should they follow the footsteps of their guru, Dr Fixx, and drop dead in their track shoes.

Seems a sensible idea as I struggle on in the sun. Maybe "Medicalert" or "SOS Talisman" would include middle aged, middle distance jogging among their conditions requiring immediate identification and international assistance in the event of systems failure?—DENIS GILL, professor of paediatrics, Dublin.

A matter of life and death

He was an attractive young man in his late twenties. He had an educated Oxbridge accent, with slight modifications. His medical disability was a minor one—a little rectal bleeding from a small tear at the anal margin, a very suitable case for a surgeon of average competence. My first three days of treatment were an outstanding success, with great satisfaction to surgeon and patient alike, and a cure seemed round the corner.

On the fourth day, however, there was great sadness and I was shown, with real visual proof, that the bleeding had recurred. He was outwardly distraught and I was somewhat disappointed. Nevertheless, another three days of my special treatment and we were on the way to recovery; but, sadly, on the fourth day the condition had recurred with further blood loss.

His outward disappointment was very touching. This story went on repeating itself for some weeks, with no success on my part. One began to suspect that there was what in the trade is called patient non-cooperation. The answer turned out to be an easy one: he happened to be a German spy. He was in fact a native of another non-involved European country and had been educated in England. He had been in the Royal Herbert Hospital in Woolwich for many months before I took over. He had worn out all my predecessors. Our object of course had been to get him well so that he could be shot; his was not to get well so that he would not get shot. It was just as easy as that.

May I say that, although I was in charge of him for several weeks, he still came out the winner, and as far as I know kept his small lesion, as his life line, active till peace was declared. I suppose I would have done the same. It was easy for him to spend half an hour in the middle of the night opening up the small tear and providing a good show of blood on the sheets for all to see. King's Regs (now Queen's Regs) VI-113 required that any one with a medical problem must be in hospital—not prison—and must be examined every day.—SIR IAN FRASER, Belfast.