Needs and Opportunities in Rehabilitation

Rehabilitation in rheumatic diseases

DAPHNE GLOAG

"Someone to look after the whole patient, not just the part that hurts" was how one consultant summarised the medical needs of patients with rheumatic disease. Another described rehabilitation as pulling together the relevant information and pointing the patient in the right direction—for much is known and much is available. Yet both patients and general practitioners tend to have low expectations of services and low levels of demand.1 Even worse, nearly a quarter of health districts in 1982 had no specialists in rheumatology and others had minimal specialist help.1 As many as 42% of arthritics in a study done in the early 1970s could have been helped by specialist advice and treatment had it been offered at an earlier stage; the position is not thought to be greatly altered today.

One consultant I talked to was worried about more attention being given to drugs than to the patients' functional disability: while occupational therapists would spot the disability they were in short supply and not always called in when needed, and it might not be so obvious to the doctor when a patient was getting steadily less able to do anything. There was not enough specific questioning about activities and problems, he thought, at clinics; and this kind of insidious deterioration, which was not regarded as a crisis, meant that such patients tended not to have good enough services. On the other hand an immunologist concerned with rheumatoid arthritis spoke of the opposite danger—paying more attention to rehabilitation than to getting drug treatment right.

Some 20 million people a year are suffering from some sort of rheumatic complaint and over 8 million consult their doctor; more than 1 million are impaired by one of these diseases and over 200 000 severely disabled.2 In the context of these figures the deficiencies in services point to a great burden of unalleviated distress—"opportunities foregone and pain and difficulty left without mitigation."3

In this article space does not allow me to look at many individual conditions, and I refer most often to rheumatoid arthritis; but clearly osteoarthritis, especially of the hips and knees, is a large problem, and spinal disease is very important.

The aims

Rehabilitation in rheumatic diseases is concerned, as in any chronic disabling condition, with the total life situation. "It is the outcome over the long haul that is of greatest importance" (p 293), and there is the problem of long term motivation; the battle is won and lost, a consultant said, in the mind of the patient—who must cooperate with professional help and believe in the rehabilitation process. A good rapport between doctor and patient is important here. In rheumatoid arthritis the unpredictability is also a problem, and depression and anxiety are common, especially in young people and in those with mild or moderate disease.4 Scarce resources as well as sound rehabilitation philosophy point to a strategy of enabling the patient to cope for himself (p 298). But this implies effective help and counselling, preferably early on. With the total care approach and early referral, falls in the proportion of near complete cripples from 25% to 5% in rheumatoid arthritis, and from 15% to 1% inankylosing spondylitis, have been reported (de Blecourt et al5), and consultants I have met have also spoken of improvement.

Here rehabilitation is also prevention—it is not an endstage affair, after the event, in these diseases, as a consultant said to me: the techniques must be used continuously right from the start and they merge into treatment. In rheumatoid arthritis, for example, drugs treat the inflammatory state and reduce pain, making movement more tolerable; joint protection—rest as appropriate and avoiding harmful positions for the joints, including the use of aids—is both restoration and prevention, and so is physiotherapy for preserving function: attending to joint range and “keeping the muscles in good nick.” This rheumatologist depicted rehabilitation as on three levels, all aiming at the optimum independence and quality of life: firstly, preventing disease progression so far as possible through joint protection and physical methods; secondly, joint replacement where necessary; and, thirdly, for those who do end up disastrously crippled all possible aids and adaptations—including if necessary "remote controlled everything." He thought that Possum environmental control systems, though widely used for paraplegics, were not considered often enough for arthritic patients.

Coping with life

For the actual business of coping with life the basic needs are general counselling—taking account of psychological, family, and social problems as well as the practicalities of living and how to adapt to disability with the maximum independence—and a detailed look at all the things that might need adjustment such as the layout of the home and perhaps work place and the organisation of the day. It is futile and infuriating to advise the busy housewife to rest, says Chamberlain;6 but ways of easing difficult tasks and schedules can be found. Patients' own dissatisfaction in the activities of daily living need to be properly assessed. Advice about good and bad positions for the joints and posture, with thought about furniture and kitchen arrangements, is given by occupational therapist and physiotherapist. For people with disease of the hips and knees high chairs (see next article) and toilets and also beds of the right height can make an enormous difference. Home visits by occupational therapists in connection with aids and methods of coping and by health visitors or social workers all provide important opportunities—assessing and talking about psychological and social problems, and spotting the need for more counselling, are obviously easier in such a setting.

Clearly it is unrealistic to suppose that everyone in need will have this kind of total help—especially the increasing numbers of elderly people with their worsening osteoarthritis. One district general hospital I visited has direct access to occupational therapy

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Exercises

“They need to get into the habit of doing their exercises at least morning and evening just like cleaning their teeth” was how one physiotherapist put it. A view that has come into vogue, however, among physiotherapists is that instructing about activities that are part of ordinary life and can become exercises, such as getting out of a chair in a particular way, will have a more lasting chance of success. Exercises are to help joint mobility, prevent deformity, and maintain the range of movement that was lost due to pain and stress on affected joints as well as improving strength—and they need to be individually tailored. They are divided broadly into isometric exercises to build up muscles, active or passive exercises to maintain or improve a range of movement, and possibly activity to promote general fitness, especially in younger patients. Increasingly the physiotherapist’s role is to educate, advise, and monitor more than to hand out therapy. Although physiotherapists are not plentiful there should be enough for this task, at least so far as patients referred to hospital are concerned. More direct referral by general practitioners to a physiotherapy department would enable many more people to be helped—for example, those with early osteoarthritis who might otherwise wise not be seen, but who can simply be instructed (perhaps with a relative) in exercises that might alter the course of their affliction. More and more hospitals are trying, or planning, direct referral. More domiciliary physiotherapy, which has been found feasible at Northwick Park Hospital, for instance, would be especially helpful to the elderly; but resources will not always go round. Failing this, very simple measures that might be demonstrated by anyone can make a striking difference. An important example is quadriceps exercises, which (together with weight reduction if needed) might mean that someone with arthritis of the knees can get up from a chair instead of becoming chairbound (p 370).

A recurring theme is that a physiotherapy course should imply careful assessment: is it needed in the first place, should it continue, and should a refresher course be given? Physiotherapy
Box 1

Two series of publications on aids

Equipment for the Disabled is a series of 12 reference books providing full details and independent comment (based on expert assessment and, mostly, users' experience) on the wide range of aids and equipment available. Each entry includes an illustration and addresses of manufacturers or distributors. The books also cover everyday consumer products that can make life easier, and describe simple devices that can be made in a hospital department or at home. Each section of every book includes general information and guidelines to help in the selection of an aid, together with suggestions for solving many problems and for coping with difficulties. Every three or four years each book is revised. The subjects covered are incontinence and stoma care; outdoor transport; communication; wheelchairs, hoists, walking aids; housing and furniture; home management; clothing and dressing for adults; leisure and gardening; personal care; disabled mother; disabled child. Published at £3·50 each (plus postage and packing) by the Oxfordshire Health Authority for the DHSS, the books may be obtained from Equipment for the Disabled, Mary Marlborough Lodge, Nuffield Orthopaedic Centre, Headington, Oxford OX3 7LD.

Disabled Living Foundation information lists cover 20 broad subjects—beds; pressure relief; chairs; communication aids, including some computers; and organisations concerned with sensory and speech impairment; remote control apparatus, emergency call systems, intercoms, and telephone aids; eating and drinking aids; hoists and lifting equipment; leisure activities; personal toilet; personal care; transport, including tuition; walking aids; wheelchairs; household equipment; household fittings; incontinence; clothing; footwear; children's aids; children's furniture. The lists contain brief descriptions of the items with addresses of manufacturers or major suppliers, or both, together with other relevant publications. They are revised annually, with bimonthly updatings. Lists cost 75p each, including postage (or complete sets may be supplied by subscription), and may be obtained from the Disabled Living Foundation, 380-4 Harrow Road, London W9. The DLF also publishes other information papers, booklets, and books and provides an information service.

should not be used as a placebo, points out Chamberlain, when all else fails. "It may be used as a rubbish bin," one physiotherapist said to me, "and it is sometimes forgotten that if six weeks do no good three months won't help either." She herself attended outpatient clinics with the rheumatologist, and courses were prescribed as needed rather than according to a set plan—"We call back patients who look blank when you mention exercise as well as the ones who are deteriorating."

The inevitable rationing of physiotherapy, however, means that help is denied to many. One consultant told me that shortages had forced him to abandon the system of regularly reviewing his patients with rheumatoid arthritis for repeat physiotherapy courses. Hydrotherapy is often enjoyed and found helpful but is not widely enough available. I know of one pool in a district general hospital that is threatened with closure for lack of money. There may also be psychological benefit in formal physiotherapy. A woman with rheumatoid arthritis I met would have liked the encouragement of further courses but she knew that it was up to her now and that she was "not bad enough." She was then attending an acupuncturist. At the beginning of physiotherapy an encouraging and warm atmosphere can make all the difference. A physiotherapist in the east end of London said that the local population was not exercise oriented and patients might drop out after a single visit, but by being offered the bribe of welcome heat treatments they were encouraged to stay the course and be indoctrinated about exercises.

Home exercises, however, practised daily, were just as beneficial as outpatients physiotherapy in a study in Leeds. This used just two simple exercises with graduated weights, with three initial sessions for instruction. One problem is the sheer difficulty of persevering on one's own in the face of pain and often poor health. A sheet of exercises to follow is not enough. The Leeds study showed that home exercises are doomed to failure unless patients know that they are going to be assessed at a follow up visit and have a diary for recording progress. Family encouragement may also, of course, be important here.

Physical training that includes general conditioning to improve fitness seems not to be normally advocated in Britain for the common rheumatic diseases. It can be difficult clearly for the elderly with established osteoarthritis (though it should be important in the early stages); a man of 62 with osteoarthritis of one hip was, however, enabled to walk at over 8 kilometres an hour with crutches (compared with 3·5 km/h without), at 85% of his maximum oxygen intake.10 Those with rheumatoid arthritis, of course, tend to be in poor general health with little energy—though doctors may try to get them going. Some interesting work on physical activity in inflammatory rheumatic disorders has been done in Scandinavia. A review article recommends training programmes to improve poor physical condition and mental wellbeing, to build up a reserve to fall back on in bad periods, and to train joints and muscles not yet affected: they should be designed to keep the load on joints to a minimum, using swimming in warm water; easy cycling, hiking, or skiing; walking and gentle jogging on soft surfaces; or gentle games or dancing. At the Karolinska Hospital, Stockholm, patients with rheumatoid arthritis aged 38-69 (mean 56) years pursued for from four to eight years a training programme consisting of fortnightly group exercises plus bicycle ergometer training at home or, as time went on, their own varied activities for an average of nearly six hours a week except during exacerbations.11 Radiography of the joints, physiological tests, and various clinical measures all showed the "trained" group to be in a significantly better state than the matched controls (though I have heard scepticism of the validity of a controlled trial in this context). Capacity for the activities of daily living correlated with amount of training.12 The authors conclude that even in rheumatoid arthritis it is better to be overactive than undereactive. Some rheumatologists I have met have been dubious about this from various points of view, though swimming and perhaps use of an exercise bicycle are favoured forms of activity. Such a programme would be undesirable, it is felt, if practice it overshadowed the healing potential of rest for acutely inflamed joints.

Joint replacement

For some people with arthritis the best rehabilitation is clearly surgery. The transformation that can be achieved by joint replacement is illustrated by the case of the 62 year old man I referred to above: while the mean energy cost of walking at 3·5 kilometres an hour was 205 kJ (49 kcal) before hip replacement, it had fallen to 130 kJ (31 kcal)/km nine months afterwards, so that the loss of efficiency due to arthritis had been around 58%.16 By this time he could walk at 8 km/h without a stick.

The snag is the long waiting time, often running into years for hip replacement, especially where beds are not separated from those for accidents. The Duthie Committee commended systems such as those at the Nuffield Orthopaedic Centre, Oxford, and the Royal East Sussex Hospital, Hastings, resulting in a faster throughput of orthopaedic patients20; the latter, which depends on "total care" planning before operation plus intensive rehabilitation, I will describe in a later article on rehabilitation of the elderly.

At Dorking General Hospital in Surrey, where separate
operating lists for joint replacements help to keep down waiting times (the record is 24 hours), printed schedules for all categories of staff ensure a consistent approach to postoperative care and rehabilitation in the face of staff changes.

**Conclusion**

Even small gains in function, say Chamberlain and Wright, can make all the difference to independence.1 Hence a better spread of the various rehabilitation approaches and services, modest enough in themselves, should be cost effective. But the resources are not enough and are not going to increase. The quality of present services is maintained, de Blecourt and others point out, only because they are not universally available. Greater equity, they say, must come from greater economy of effort, with "profound adjustments" in the roles of all professionals—much of whose activity should be concerned "less with doing and more with teaching others how to apply the knowledge that emanates from their skills and experience." An occupational therapist I met strongly objected to this principle as a cheap way out. Nevertheless, in the absence of sufficient occupational therapists (or whatever is in short supply) the only way forward lies in finding a method of helping the primary care team to offer some version of the service concerned when possible. No less important, de Blecourt et al urge a more explicit pinpointing of the immediate aims in each case, so that all members of the team and also the patient, his family, and any others concerned can have a clear contribution to make.1

Cost effectiveness could also be helped by knowing from the start who most needs help. Approaches to measuring outcome in rheumatoid arthritis have been developed.21 Where is it that interventions make most difference? Research evaluating some rehabilitation procedures could point to economies. In a limited study referred to by de Blecourt et al a group receiving inpatient care without follow up or specialist guidance thereafter fared significantly worse than those having outpatient care for whom community services were mobilised.

A glaring deficiency in the services is the lack of consultant rheumatologists in many districts. This means among other things that GPs and other professionals lack what Wood and Badley call a vital educational resource, without which the primary care team cannot easily play its full part; furthermore, without a specialist there may be no one to organise and coordinate services—with the resulting neglect of possibilities.1 In the past there have been not enough people in training to increase the number of specialists but according to the study by Wood and Badley this has now changed.1 Fully trained senior registrars are waiting for consultant appointments, but although new posts have been approved in some cases they have not been funded by the regions concerned.

Too many people struggle on heroically, believing that nothing much can be done to improve their lives; and yet there are so many possibilities, often simple, that could make things better. As so often with rehabilitation, more awareness of what is possible is one of the great needs.

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**Addresses**

Arthritis and Rheumatism Council and Arthritis and Rheumatism Council for Research 41 Eagle Street, London WC1R 4AR

Association to Aid the Sexual and Personal Relationships of the Disabled (SPOD) 286 Camden Road, London N7 8BJ

British Rheumatism and Arthritis Association and Arthritis Care (welfare charities) 6 Grosvenor Crescent, London SW1X 7ER

Disabled Living Foundation 380-4 Harrow Road, London W9

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**Box 2**

**Aids centres**

Aids centres provide information to those professionally concerned with disability and to disabled people and their relatives, and they display a selection of aids that can be inspected and tried out. **Intending visitors should always make an appointment.**

**Belfast** Aids Centre, Rehabilitation Engineering Unit, Musgrave Park Hospital, Stockman’s Lane, Belfast BT9 7JB (0232 669501)

**Birmingham** Disabled Living Centre, Broadgate House, Broad Street, Birmingham B1 2HF (021 643 0890)

**Blackpool** Blackpool Aids Centre, 8 Queen Street, Blackpool FY1 1PD (0253 21084)

**Caerphilly** Aids and Information Centre, Wales Council for the Disabled, Caerphragly Industrial Estate, Bedwas Road, Caerphilly CFI 35L (0222 887325)

**Edinburgh** South Lothian Aids Distribution and Exhibition Centre, Astley Ainslie Hospital, Edinburgh EH9 2HL (031-447 9200)

**Glasgow** Aids Advice and Resource Centre, Florence Street Clinic, 26 Florence Street, Glasgow G41-429 2878

**Leeds** William Merritt Aids and Information Centre for Disabled People, St Mary’s Hospital, Greenhill Road, Leeds LS12 3QE (0532 790121)

**Leicester** Medical Aids Department, British Red Cross Society, 76 Clarendon Park Road, Leicester LE2 3AD (0533 700747)

**Liverpool** Mersseyside Aids Centre, Youens Way, East Prescott Road, Liverpool 14 2EP (051-228 9221)

**London** Disabled Living Foundation, Aids Centre, 380-4 Harrow Road, London W9 (01-289 6111)

**Manchester** Greater Manchester Regional Centre for Disabled Living, 26 Blackfriars Street, Manchester M3 5BE (061-852 3678)

**Newcastle upon Tyne** Newcastle upon Tyne Council for the Disabled Aids Centre, Mea House, Ellison Place, Newcastle upon Tyne NE1 (0632 323617)

**Portsmouth** Disabled Living Centre (Portsmouth and Districts), Prince Albert Road, East Portsmouth PO4 9HR (0705 737174)

**Southampton** Southampton Aids Centre, Southampton General Hospital, Tremona Road, Southampton S09 4XY (0703 772222 ext 3414 or 3233)

**Sheffield** Sheffield Aids Centre, Family and Community Services, 87-9 The Wicker, Sheffield 5 8HT (0742 737025)

**Stockport** Stockport Aids Centre, St Thomas Hospital, 59a Shaw Heath, Stockport SK3 8R 1BL (061-480 7201)

**Swindon** Swindon Aids Centre, The Hawthorn Centre, Cricklade Road, Swindon, Wilts SN2 1AF (0793 43966)

**Wakefield** National Demonstration Centre, Pinderfields Hospital, Aberford Road, Wakefield (0924 75217 ext 2510 or 2263)

**Travelling exhibitions**

**Mobile Aids Centre** Scottish Council on Disability, Princess House, 5 Sandwick Place, Edinburgh EH2 4RG (051-229 8632)

**TRAVELLING EXHIBITION OF AIDS FOR INDEPENDENCE Royal Association for Disability and Rehabilitation, 25 Mortimer Street, London W1N 8AB (01-637 5400)

**Visiting Aids Centre** St Francis Society, 16 Fitzroy Square, London W1P 5HQ (01-387 9571)

For details of proposed new aids centres contact:

**Joint Aids Centres Committee** (Mrs Ann Crumblie) c/o Medical Aids Department, British Red Cross Society, 76 Clarendon Park Road, Leicester LE2 3AD (0533 700747)
For Debate . . .

Why do our hospitals not make more use of the concept of a trauma team?

J D SPENCER

Emergency aid at the roadside—maintaining an airway, giving oxygen and intravenous fluids—undoubtedly saves lives, and in some areas of the United Kingdom consultants in accident and emergency have set up mobile teams to give immediate aid to the victims of road traffic accidents and for other acute injuries. In remote areas this care may be provided by general practitioners who have formed themselves into “on call” teams. Once immediate aid has been given, seriously injured patients need to be transferred from the roadside to an accident centre as smoothly and rapidly as possible. A particularly well-coordinated scheme has been reported from Maryland, where an integrated system of ambulances and helicopters transfers patients to the appropriate referral centres.1

In many areas of the United Kingdom, however, severely injured patients are unlikely to receive immediate care at the roadside from medical practitioners. Instead, they are transported by ambulance directly to the nearest district general hospital or teaching hospital. There the patient will be assessed, usually by the casualty officer, and some form of treatment given before a specialist team is called in to deal with specific injuries. This system, although hallowed by tradition, is often unsatisfactory because an inexperienced casualty officer may fail to make the appropriate diagnoses.2 Thus a ruptured spleen, a subdural haematoma, a diaphragmatic hernia, or a haemopericardium may be missed, for physical signs are difficult to elicit in the unconscious patient and extensive surface bruising may not be apparent for many hours after the accident.

Some hospitals, such as the Birmingham Accident Hospital, have sought to improve their standard of care by ensuring that senior medical staff are concerned from the outset. Thus patients are admitted and seen immediately by surgeons specifically trained in all branches of accident surgery.3 Furthermore, a consultant is available on site 24 hours a day. Such a system may be ideal, but most district general hospitals cannot provide such a service unless they have designated regional accident centres.4

In an attempt to improve the standard of care for the severely injured at Lewisham Hospital (a busy district general teaching hospital) we have organised a “trauma team,” which gives immediate support to the casualty department. The team was formed to ensure that the simple rules of resuscitation and diagnosis in severely injured patients were followed and that, in a hospital

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References