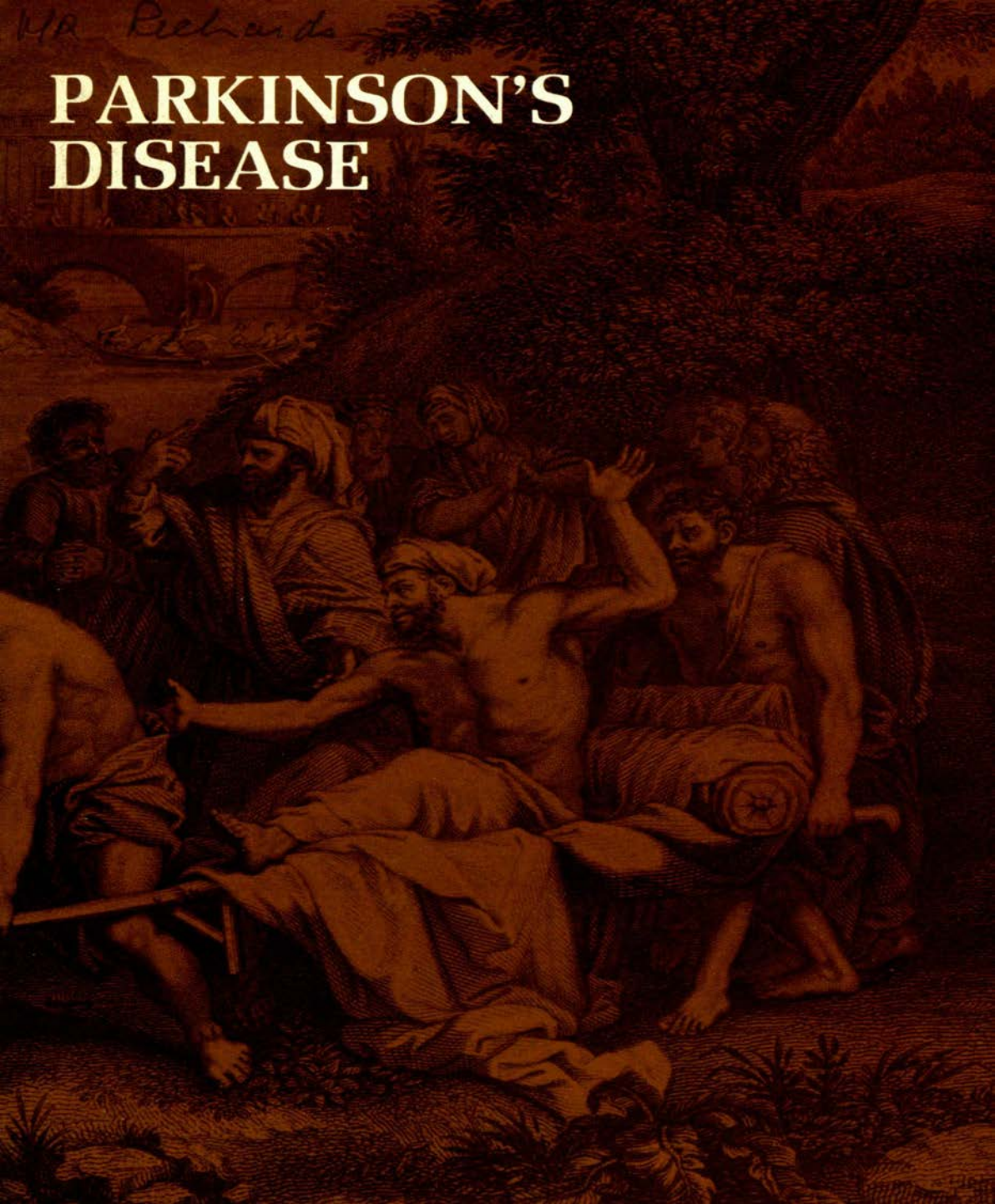


W.A. Richards

# PARKINSON'S DISEASE



Cover *'Then saith he to the sick of the palsy, arise, take up thy bed and go into thine house'* St Matthew IX, 6

# PARKINSON'S DISEASE



**Office of Health Economics**

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## Office of Health Economics

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- To investigate other health and social problems.
- To collect data from other countries.
- To publish results, data and conclusions relevant to the above.

The Office of Health Economics welcomes financial support and discussions on research problems with any persons or bodies interested in its work.

## Introduction

Parkinson's Disease has probably occurred amongst elderly people throughout history. But it is now a more serious burden to society than at any time in the past because the development of modern medicines coupled with the improvement in living standards in the industrialised countries has largely eliminated the traditional major threats to health such as the infectious diseases. The consequent rise in life expectancy has led to marked increases in the prevalence and significance of the chronic, disabling conditions of old age.

Parkinsonism and the personal and social problems it creates typifies such illness. Although recent advances in treatment, most notably the introduction of L-dopa, have gone some way to relieving the distress it causes it remains an incurable condition, at least in the sense that diseases such as tuberculosis can now be cured by the elimination of the causative agent. As with many other degenerative conditions which affect people mainly in later life medical and social care must aim primarily at the alleviation of the patient's handicaps and, where possible, the prevention of further limitations to the individual's freedom in life.

Considered in isolation none of the major symptoms of Parkinson's Disease are associated exclusively with the condition, a factor which sometimes leads to confusion regarding the definition and identification of the disease amongst the general public. For example, the development of tremor in, say, the hands of elderly people may have many causes other than Parkinsonism. Yet the full clinical picture usually presents an unmistakable pattern. And although in a minority of cases Parkinson-like syndromes may be attributed to various known causes, such as the side effects of certain medicines (fortunately reversible), pathological investigations show that Parkinson's Disease may be considered to be a specific neurologic disorder of as yet unknown aetiology. Such idiopathic Parkinsonism probably affects 60–80,000 people in the United Kingdom, the great majority of them aged over 60 years.

This paper describes the symptoms, occurrence and, as far as they are known, the causes of Parkinson's Disease in order to clarify the extent and nature of the problems the condition generates in our society. It also examines questions relating to the organisation and objectives of the National Health Service and the Local Authority social services.



## The nature of Parkinson's Disease

Parkinson's Disease derives its name from the English physician James Parkinson who described the conditions in his *Essay on the Shaking Palsy*, which was published in 1817. He wrote that it was characterised by 'involuntary tremulous motion, with lessened muscular power, in parts not in action and even when supported, with a propensity to bend the trunk forward, and to pass from walking to a running pace. The senses and intellects being uninjured'. Although Parkinson made no mention of one of the main symptoms, muscular rigidity, and could of course only guess at the physiological roots of the disease his work is still widely regarded as a major element in the emergence of modern standards of clinical observation and analysis and was clearly a significant contribution to the general development of scientific method in the early nineteenth century.

Today Parkinson's Disease is recognised as having three main symptomatic components, any one of which may dominate a particular case. These are tremor, that is shaking of the limbs or the head, slowness of, or even inability to initiate, movement and muscular rigidity leading to a characteristically bowed posture and immobile face. Other aspects of the condition frequently include alimentary disorders with constipation. And the skin may become excessively greasy and inability to swallow excess saliva may lead to drooling.

In that these symptoms and others related to them become progressively more apparent, usually over a period of years, and suggest the effects of old age rather than any specific disease, people with Parkinsonism are sometimes thought of as being senile. This is undesirable as, on the whole, their minds remain unimpaired although changes in mental state, such as periods of intense depression, may often be attributable to the disease or its treatment. So too, occasionally, may be some cases of dementia (Davison 1974, *BMJ* 1974) although such a diagnosis in elderly, disabled and possibly profoundly depressed individuals must be regarded with caution.

The 'mask-like' face of a person suffering from Parkinson's Disease, which commences in the early stages with abnormal changes of facial expression rather than a complete lack, has the sometimes unrecognised disadvantage of preventing the normal indication of feelings through, say, a grimace or a smile. This is an important barrier to communication because, to a person ignorant of the effects of Parkinson's Disease, the resultant blank look on the features of someone with the complaint does not simply fail to pass on an expected response but may often suggest an unintended one such as a lack of interest in, or rejection of, the observer (or mental impairment which does not in fact exist). Failure to recognise such early symptoms may often lead to unnecessary distress.

Physically based problems like a reduced ability to communicate may exaggerate any decline in the mental state of someone with Parkinson's Disease so that a vicious cycle builds up, being comprised of disablement leading to psychological and social problems, like loss of occupation or breakdown of close personal relationships, leading in turn to loss of will and further physical limitations.

Even without such exacerbations Parkinsonism is potentially highly disabling. About two-thirds of those who suffer it for ten years become very dependent on physical assistance from others during that period. Even tremor alone can cause handicap. As Parkinson himself pointed out 'the motion becomes so violent as not only to shake the bed hangings but even the floor and sashes of the room'. However, tremor can be treated, either medically or in a few cases surgically, and it is normally reduced by voluntary movement or in sleep. Hence by no means all those with tremor need fear its developing to such an extreme degree.

The greater part of handicap resulting from Parkinson's Disease usually stems from its effects on individuals' ability to perform the fine movements involved in writing or dressing and the many other activities necessary for independent life. For example, loss of balance combined with difficulty in starting voluntary movements and slowness in carrying them out (bradykinesia) and the postural defects caused by muscular rigidity can cause patients to have great difficulty in walking, some being unable to rise from a chair or even to turn over in bed.

Parkinsonism may contribute to an early death, which is usually due to some identifiable intervening factor. In only a tenth of all cases is the disease itself recorded as a main cause of mortality. Life expectancy is on average in the region of nine years after the onset of symptoms (Hoehn and Yahr 1967) although this is subject to considerable variation. It may be pointed out that the late age of commencement of the condition (on average about 65 years) usually means that the overall longevity of people with Parkinson's Disease is as great as that of average members of the population despite raised mortality rates after the disease has been contracted. Only where the onset of handicap is very rapid is an early death likely. From the viewpoint of a person with the illness, or their relatives, they should prepare themselves to combat the problems of progressive disability rather than to face premature death.

### Causes

Parkinsonism is associated with the degeneration of parts of the basal ganglia and brain stem nuclei, areas of the brain known to be closely involved in the control of movement and posture. The 'substantia nigra' is particularly affected, losing its normal pigmentation and also large numbers of nerve cells, although less specific and more widespread brain changes are also usually present. No



primary extra-neuronal or other general pathological effects have been observed.

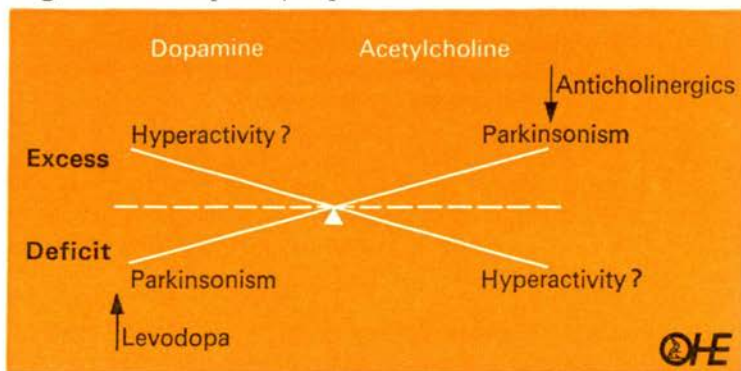
These brain changes are of unknown aetiology in idiopathic Parkinsonism although certain Parkinsonian syndromes are associated with noxious substances, such as carbon monoxide or manganese in high concentrations, trauma or the sequelae of encephalitis lethargica (sleepy sickness).

Post-encephalitic Parkinsonism was first described by von Economo in 1929. All the known cases stem from a world-wide epidemic of encephalitis lethargica which ended in about 1930. They have a characteristic pattern of evolution which often includes an unusually rapid and early onset of Parkinsonism and are also identifiable by their response to therapy, some atypical symptoms and by pathological abnormalities.

A number of medicines, notably the major tranquillisers belonging to the phenothiazine group as well as the butyrophenones, reserpine and methyl dopa can also induce a form of Parkinsonism. These effects are reversible with withdrawal of the drug concerned.

Briefly considered the significance of the general pathological findings in Parkinsonism lies in the fact that it is now known that transmission of impulses across junctions between nerves (synapses) is facilitated by substances known as neuro-transmitters. (These include adrenaline and noradrenaline, serotonin, acetylcholine and dopamine.) These different chemicals are found to be used separately in distinct parts of the nervous system, although their actions may be complementary so that a balance in their various distributions is demanded. An example of this is that it is thought that certain

**Figure 1** *The dopamine/acetylcholine balance*



*Note* The true image is complicated by the role of other neuro-transmitters such as 5HT and noradrenaline (to which dopamine is the precursor). The complex balances between these chemicals in the brain are not understood in detail. Parkinsonism may in part be a result of receptor pathology rather than straightforward shortage of dopamine.



dopamine dependent brain functions have inhibitory effects which normally balance those facilitated by the action of acetylcholine (see Figure 1).

It was shown by Ehringer and Hornykiewicz in 1960 that sufferers of Parkinson's Disease show depleted levels of dopamine, the neurotransmitter normally found in marked concentrations in the part of the brain most affected by the illness. Thus research in the early and mid-1960s aimed at correcting this deficiency.

Suggested mechanisms involved in the brain changes associated with idiopathic Parkinson's Disease have ranged from unusually rapid ageing or a chronic metabolic defect, possibly genetically determined, to the excess accumulation of heavy metals in the affected parts of the brain (Parkes *et al* 1972) or an abnormal production of a hormone with regulatory functions in the brain (MSH) linked with a poor ability to synthesise dopamine (Shuster *et al* 1973). It has also been postulated that encephalitis lethargica may be a causal agent in cases of paralysis agitans as well as in post-encephalitic Parkinsonism (Poskanzer and Schwab 1963), although this hypothesis is rejected by many authorities.

Finally, although the term 'arteriosclerotic (or more precisely atherosclerotic) Parkinsonism' has been in use since the 1920s it is no longer generally accepted that atherosclerosis can cause Parkinsonism. Although Parkinson-like syndromes could theoretically be directly causally related to cerebral atherosclerosis this belief most probably stemmed from either the chance association of two fairly common diseases of the elderly (idiopathic Parkinsonism and cerebrovascular disease) or from occasional examples in which patients suffering from gross generalised atherosclerosis happen to exhibit some symptoms of the Parkinsonian syndrome. There is no available evidence to show that paralysis agitans has as a specific cause cerebral atherosclerosis.

## Epidemiology

The prevalence of Parkinsonism has been investigated in a number of recent surveys, the most widely known and quoted of these being those conducted in Rochester in the United States and Carlisle in England. As may be seen in Table 1 Kurland's Rochester study found a considerably higher prevalence of Parkinsonism at all ages than did the Carlisle research, his rate amongst those over 50 years of age being nearly 1 per cent whilst that of the latter was approximately 0.3 per cent. The discrepancy in annual incidence rates over the whole population was 12.1 as opposed to 23.8 per 100,000. As Figure 2 shows the data from the only other study likely to have recorded the full numbers involved, which was carried out in

**Table 1** Age-specific prevalence (per 100,000) of Parkinsonism**Rochester, Minnesota (1955)**

Age	Population at risk	Number of cases	Prev. rate /100,000
0 - 49	22,209	1	5
50 - 59	3,347	8	239
60 - 69	2,505	19	758
70 - 84	1,635	23	1,407
85 +	189	5	2,646
All ages	29,885	56	187
60 +	4,329	47	1,086

**Carlisle (1961)**

0 - 39	39,968	0	0
40 - 49	9,681	14	144.6
50 - 59	9,268	15	161.8
60 - 69	7,297	23	315.2
70 - 79	3,738	23	613.7
80 +	1,149	5	443.9
All ages	71,101	80	112.5

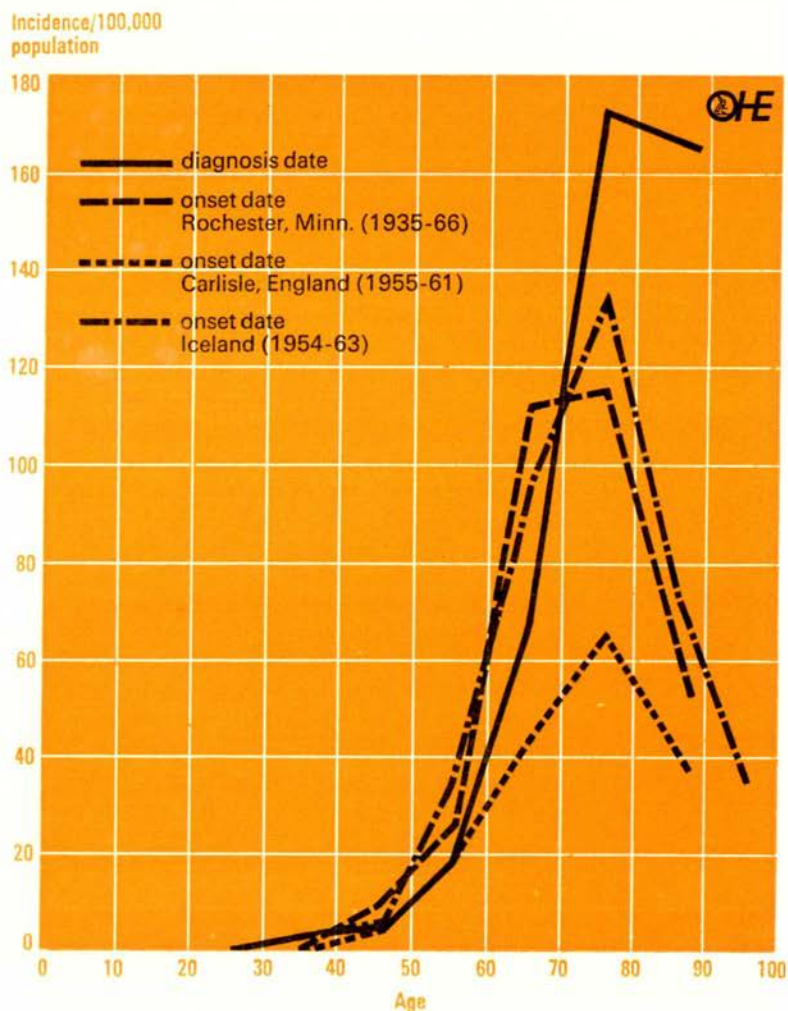
Sources: Kurland *et al* 1958 Brewis *et al* 1966

Iceland in 1963 (Gudmundson 1967), supports the American rather than the English figures.

It is thus probable that the Carlisle figures somewhat underestimate the true prevalence, as was suggested by the authors (Brewis *et al* 1966), and that the overall rate is likely to be in the region of 150 per 100,000 population with the prevalence amongst persons over 50 years of age being in excess of 500 per 100,000. If this is so then the estimate of 60,000 people suffering from Parkinsonism in the United Kingdom which is currently widely quoted is probably too low, perhaps by as much as 20,000. Hence the proportion of people who may now, on today's survival rates, be expected to develop Parkinsonism at some time in their lives may be near to one in 100.

However, it must be pointed out that in general the epidemiological information on Parkinson's Disease is inadequate. For example, particular local factors could perhaps invalidate national or international extrapolations based on current figures and survey findings should be treated with caution because varying diagnostic criteria and case-tracing techniques have often been employed (mortality and hospitalisation rates, for example, are subject to misinterpretation). Also factors such as the possible influence of

**Figure 2** Averaged age-specific incidence rates (per 100,000) of Parkinsonism



Sources Nobrega *et al* 1967 Brewis *et al* 1966 Gudmundson 1967  
(Original compilation Kurland and Kurtzke 1972)

infective agents in the incidence of idiopathic paralysis agitans may distort findings. Certainly the increasing mortality amongst the last generations to have experienced the most recently recorded epidemic of encephalitis lethargica is leading to falls in the prevalence of post-encephalitic Parkinsonism.

9 In this context some researchers have argued that the available



epidemiological evidence regarding the age of onset of Parkinsonism supports the theory that von Economo's disease may be the underlying cause of Parkinson's Disease itself. (Which if correct would suggest that a marked fall in the incidence of new cases might be experienced in the relatively near future.)

Both Poskanzer and Schwab in the United States (1963) and Brown and Knox in the United Kingdom (1972) have published findings indicating an annual increase in the age of onset of Parkinsonism which they attribute to the increasing length of time since the encephalitis lethargica epidemic in the 1920s. However, other interpretations of the data are possible. It may be that, after the initial dilution of the pool of Parkinson patients in the 1930s by those suffering from the post-encephalitic form in relatively early years, the recently reported increases in the age of onset may be attributable to improved recognition and specialist treatment of Parkinson's Disease amongst previously neglected groups of elderly people (Kurland *et al* 1973). There is strong clinical and pathological evidence implying that post-encephalitic Parkinsonism and Parkinson's Disease are quite different entities and it is also probable that the average age of onset of the latter today is similar to that recorded before the 1920s.

Similarly other suggested links between Parkinsonism and race, smoking and possible decreased vulnerability to cancer are unproven, although Kessler's work in Boston (1971, 1972) does suggest that the intake of nicotine may have some influence on brain amine synthesis in addition to its known, direct effects on the nervous system. His findings that negroes are markedly under-represented in hospital attendances for Parkinsonism may, however, probably be explained by social factors rather than a racial variation in the incidence of Parkinsonism. Yet figures such as those of Goldberg and Kurland (1962) who recorded a threefold variation between black and white reported death rates for Parkinsonism, although equally subject to error, support the possibility of a link with colour although at present there is no conclusive information available. But there is no scientifically based justification for believing that skin variations in pigmentation may reflect similar differences in the pigmented areas of the brain or that dopamine synthesis, storage or utilisation may be affected as a result of this.

Presently available epidemiological evidence cannot be used to show whether or not genetic factors are responsible for idiopathic Parkinsonism. The problems of methodology inherent in identifying environmental as opposed to inborn influences in disease aetiology are often underestimated. Most researchers have found a positive family history in around 20 per cent of cases (for example Gudmundson 1967). However, work such as that of Mjones in Sweden (1949) indicates that this may be an underestimate and it has been suggested that idiopathic Parkinsonism may be due to a genetically determined

metabolic defect the symptomatic effects of which only emerge in later life.

Doubts in areas such as this and questions as to whether paralysis agitans may have more than one independent cause underline the potential value of intelligently conducted epidemiological research in this field.

### Parkinson's Disease in the UK

The surveys cited above indicate that there are probably between 60–80,000 people suffering from Parkinsonism in the United Kingdom. But more specific information on the situation of these individuals and the extent of their disabilities is generally lacking. For example, the local authority registers of disabled persons living in the community do not classify Parkinsonism as a separate condition. And significant numbers of the elderly receiving care in hospitals may suffer from Parkinsonism even though this may not be traceable from the available statistics.

However, certain sources other than epidemiological surveys are

**Figure 3a** *Handicap in the community from Parkinson's Disease*



Source Harris (1971). *Handicapped and Impaired in Britain*.

**Figure 3b** *Total cases of Parkinson's Disease in Britain*



Source OHE estimates

Note The extension of L-dopa therapy since the completion of the survey work for *Handicapped and Impaired in Britain* may have significantly affected the numbers of handicapped in the community and/or the proportions into which they are divided by the degree of functional loss involved.

available from which estimates may be derived. These include figures on paralysis agitans contained in the Hospital In-Patient Enquiries and the government social survey on handicap and impairment in Britain (Harris 1971). The latter calculated that there were 22,000 (see Figure 3a) people disabled from Parkinsonism living in the community in Britain, over half of whom were severely handicapped, although today this figure is probably lower as a result of the therapeutic efficacy of L-dopa.

It may be estimated that there are about 15,000 people in Britain suffering from paralysis agitans or similar syndromes who are at present in hospital or who are receiving care in nursing homes or in institutions for the elderly. Hence this implies a residue of rather more than 30,000 (see Figure 3b) individuals with Parkinson's Disease living in the community who presumably do not feel themselves to be impaired by their illness either because of successful treatment or because it is in its early stages. Many of these may be unaware of the diagnosis.

It must be emphasised that these are crude estimates based on scant information. If effective measures of the value of therapeutic advances, such as the recent improvements in medicines discussed in the following section, are to be developed then a better knowledge of the situation and physical condition of those suffering from disabling complaints must be gained.

## Treatment

James Parkinson could see no immediate possibility of a cure for the condition he described in his *Essay on the Shaking Palsy*, stressing that his work was only intended to outline an area of research for those who were to follow him. He wrote that 'until we are better informed respecting the nature of this disease the employment of internal medicine is scarcely warranted'.

During the past 15 years some of the increased understanding which Parkinson desired has emerged and the control of Parkinsonism through the use of modern medicines has progressed rapidly since the late 1960s. The following sections examine the therapies involved in some detail and also debate how the management of this disease can best be ordered within the NHS structure.

### The role of medicines

The first effective treatment for Parkinsonism was introduced in the late 1860s when the use of the belladonna alkaloids was first advocated by Ordenstein. These block some of the action of acetylcholine and may relieve symptoms such as drooling or rigidity. Other measures such as the use of phosphorus preparations or



iodine salts were employed, even in fairly recent years, although it is extremely doubtful whether they were of any value.

The development of modern pharmacology and of the pharmaceutical industry in the last few decades had its first effects on the treatment of Parkinsonism in that after 1945 synthetic anti-cholinergics began replacing the natural alkaloids. These are still widely used, mainly in conjunction with L-dopa with which they have an additive effect, as already described in Figure 1.

Another quite widely employed medicine is amantadine, which was developed primarily for its anti-viral properties. This is useful because it stimulates the mobilisation of dopamine stored in the neurones. The amphetamines and certain other drugs have similar properties which may eventually prove to have some therapeutic application in this area.

However, by far the most important single agent now used in the chemotherapeutic control of Parkinson's Disease is L-dopa (levodopa). The introduction of this substance in the treatment of paralysis agitans, which was greeted as one of the major medical advances of the 1960s, stemmed initially from research conducted by Carlsson and his colleagues in Sweden. They showed the importance of dopamine as a neuro-transmitter in some nervous system centres. Shortly afterwards the discovery of depleted levels of dopamine in the brains of people who suffered from Parkinson's Disease led to a concentration of efforts designed to treat Parkinsonism through correcting this shortage.

In 1967 Cotzias and his co-workers (Cotzias *et al* 1967) achieved demonstrable therapeutic success through the oral administration of dopas in relatively large doses. Levodopa is the immediate metabolic precursor to dopamine and is therapeutically effective because it crosses the blood/brain barrier, a property not shared by dopamine itself.

There followed a period in which somewhat dramatic reports of 'recovery' from Parkinson's Disease were published in the popular press. Subsequent experience with the use of L-dopa has modified such early over-optimistic views both in the sense that its frequently disturbing side effects have become more widely appreciated and because it is now recognised that a substantial proportion of patients do not benefit from it. Even so approximately one-third of those suffering from Parkinson's Disease show a very great improvement in their condition when treated with L-dopa whilst a further third undergo a marked reduction in their symptoms. Amongst the remainder the reaction to L-dopa is disappointing. In no case is it believed that L-dopa delays the development of the underlying pathology of Parkinsonism.

Nausea and vomiting caused by L-dopa stem from its metabolism outside the brain. Until recently this was usually combatted by the simultaneous administration of anti-emetics without pyridoxine

(vitamin B6 – found also in many vitamin preparations – which aids the peripheral decarboxylation of L-dopa). Recently, however, medicine combining L-dopa with a dopa decarboxylase inhibitor has been made available by the pharmaceutical industry. This addition prevents the unwanted breakdown of L-dopa (although alternative metabolic routes to decarboxylation exist) so preventing gastric distress and related symptoms and allowing smaller quantities of L-dopa to be used.

This valuable step permits additional patients to take L-dopa in therapeutically effective doses, that is, amounts which they would previously have found intolerable. It has the added advantage of blocking the anti-therapeutic effects of pyridoxine and may also avoid any possible ill effects that the breakdown of L-dopa outside the brain may have on the heart. The only disadvantage which may be associated with the administration of L-dopa together with a decarboxylase inhibitor is that it has been suggested (Marsden *et al* 1973) that the 'on-off' effect, in which the benefits given to individuals taking L-dopa vary dramatically several times a day, might in some patients appear earlier as a result of their use. However, the situation here is uncertain and the present evidence is inconclusive. It should not be taken to imply that the availability of such therapy is not an important and valuable innovation (Marsden 1974). Present research may eventually lead to an understanding of the mechanisms involved in the 'on-off' effect(s) amongst the minority who are affected and so to more knowledge of Parkinsonism itself.

Parkinson's Disease is usually associated with a degree of mental disturbance (Loranger *et al* 1972) and may often cause depression because of its personal and social effects as well as the brain amine imbalances involved. Thus treatment today may include the use of minor tranquillisers or, in suitable cases, tricyclic anti-depressants. (Mono-amine oxidase inhibitors are strongly contra-indicated in the presence of L-dopa.) Yet although availability of such potentially beneficial medicines should not be limited simply because of 'pharmacological puritanism' their administration should not be allowed to take precedence over or to obscure the need for non-medicinal psycho-therapy and social care designed to enable patients to accept and adapt to their condition.

All the medicines normally used in the treatment of Parkinson's Disease are potent substances which carry with them the risk of unwanted side effects. For example, in addition to the problems associated with L-dopa, which include the development of hypotension, involuntary movements and mental disturbances like insomnia, confusion or the exacerbation of depression, amantadine will cause epilepsy in susceptible subjects or confusion or hallucinations in others. The anti-cholinergics have similar mental effects in perhaps a quarter of those using them as well as causing impairments or difficulties in vision, micturition and salivation and promoting



constipation. Indeed many of the symptoms commonly associated with Parkinsonism today owe their origin, at least in part, to the medicines used to treat the disease.

Despite current research on alternative therapies, such as that based on certain ergot derivatives\* (which may have advantages over treatment with L-dopa in certain circumstances) it appears unlikely that the problems associated with side effects will be solved in the immediately foreseeable future. Awareness of the hazards of chemotherapy should thus lead to caution. Yet the benefits these medicines can bring in the right circumstances outweigh by far the possible disadvantages of their use.

### **Physiotherapy and related care**

Physiotherapy is of help to people suffering from Parkinson's Disease in maintaining muscle tone and consequently their ability to be mobile and live as free a life as possible. Any prolonged break from physical activity can prove disastrous in this context and Parkinsonian patients should be encouraged to maintain a continuous régime of exercise, possibly supported by visits to local clinics where they can learn new exercises and are sometimes encouraged through group participation.

The professional knowledge of physiotherapists may also be of use in advising individuals in skills necessary for coping with their physical limitations by, for example, informing them of techniques for maintaining balance despite poor posture. Visits to or by the physiotherapists may also be of value in relieving social isolation with subsequent therapeutic effects. But the value of such services in the latter context must be weighed against the costs, not least in terms of skilled manpower, and the availability of alternative provisions. It may be argued that at present evaluative procedures in this area are inadequate.

The role of occupational therapists is related to that of physiotherapists in that their prime function is to maintain the ability of their clients to lead as full a life as possible, where necessary advising on the alternative techniques available to replace lost skills. This can include help with activities such as dressing, (e.g. special clothing fasteners or redesigned garments) housework, gardening and individual employment problems. However, it does appear that rather too often occupational therapy is still regarded as a form of sheltered care rather than as rehabilitation for active life and it remains isolated from many problems faced in the community by its tendency to be orientated towards hospital treatment.

In recent years there has been a growing awareness of the importance of physiotherapy and occupational therapy in the establishment

\*Within the next year or 18 months it is hoped that the therapeutic value of ergot-based dopaminergic agonists, used in conjunction with substances such as caffeine, will be evaluated more clearly.



of an adequate pattern of community care. Whilst there may be some considerable inter-professional dispute as to the extent that paramedical workers such as physiotherapists should be regarded as autonomous practitioners within the system of health care outside the hospitals it appears likely they will play an increasingly important and independent role in the care of disabled people in the future. Yet in the case of Parkinson's Disease sufferers such a contribution can only be made within the framework of a full clinical awareness of the condition of individual patients.

### **Surgery**

The most suitable cases for surgery are those amongst the relatively young or fit with slowly progressing disability due to unilateral tremor with few other symptoms (excepting associated rigidity). These are relatively rare and the development of improved medicines coupled with awareness of the potentially serious side effects even of modern stereotactic surgery,\* has led to a trend away from the surgical treatment of Parkinsonism in recent years.

## **The organisation of care**

Any detailed analysis of the specific problems of the diagnosis and management of cases of Parkinson's Disease would be inappropriate within the context of this paper. However, there are two general observations to be made which are of particular importance. These are, first, that an early diagnosis of Parkinsonism is usually of considerable value even though treatment is not known to affect the underlying physical development of the disease and, second, that management of Parkinsonism is now at a stage where it may be compared with that of conditions like diabetes. Although medical care cannot 'cure' it can maintain the physical condition of many sufferers in such a way as to enable them to live a reasonably full and enjoyable life.

The suggestion that the early diagnosis of Parkinsonism is desirable rests on both the experience of specialists in the area who report instances of unnecessary physical distress due to lack of treatment of early cases and on social research (Singer 1973) which indicates that if individuals developing disablement due to Parkinson's Disease are given the time and adequate education to adapt their plans and expectations to their limitations their distress may be considerably reduced. At present there is still a widespread view that it is 'kind' to delay informing a patient of the onset of an illness such as Parkinsonism for as long as possible. In practice the

need to avoid short-term psychological shock and its potential long-term consequences may seem paramount, especially when coupled with the difficulties of making any clear-cut prognosis regarding the future physical state of Parkinson sufferers. But it must be realised that failure to initiate an early process of directed psychological and social adjustment to the onset of disabling conditions in general may ultimately succeed only in increasing the strains experienced by both patients and their relatives.

A problem with regard to the establishment of 'maintenance' therapy once the diagnosis is confirmed is that many general practitioners may not be conversant with all the aspects of Parkinson's Disease and its treatment. The latter in particular can be extremely complex, necessitating the knowledge of a specialist to ensure optimum results. On the other hand those working within the context of community rather than hospital care may be better placed to observe the problems and performance of individuals in everyday life, an area where the contribution of the family doctor can be of key significance.

The 1974 reorganisation of the National Health Service may to some extent help to relieve any such difficulties by encouraging closer contact between hospital and community health services in each district although many obstacles, such as those stemming from the geographic distribution of populations and hospitals, will remain. Perhaps in the long term the development of health centres, which may eventually be able to support specialist clinics on a local basis, could provide a partial solution to the problems of liaison between 'specialists and generalists'. Pioneer work towards such an end has already begun through, for instance, the activities of Nuffield Provincial Hospitals Trust in Oxfordshire. It might also be that the future development of 'community hospitals' will be a significant factor in this area.

On a broader level the reorganisation of the health services and local government has raised a number of questions as to the effectiveness of co-operation between the health and social services. With specific reference to Parkinsonism it may be pointed out that many house-bound or semi-mobile sufferers are dependent on services from both these sources for their well being. Yet the largely unco-ordinated provision of, say, home helps from the local authorities (in areas where these are supplied in sufficient quantities to meet the demand) and NHS workers such as health visitors may lead to a number of problems. It can be argued that when dealing with people who are likely to be socially isolated more effort should be made to ensure services such as those given by the personnel mentioned above achieve their maximum effect by, for instance, spacing contacts evenly throughout the week.

Thus possible further developments in care could hinge on the development of adequately linked records of treatment or support-



tive services being established jointly by local authority social service departments and the NHS at Area level. Area and District Nursing Officers, District Community Physicians and Area Medical Officers could play an important role in such a development, working with the District Co-ordinators and Liaison Officers at Area level who are being appointed by the social service departments.

An additional point to be recognised is that the need of chronically ill people to build up long-term personal relationships with those helping them, especially in potentially sensitive areas such as the maintenance of personal hygiene, should be recognised. Just as the appropriateness of many of the divisions of function between health and social service workers may be questioned, so too may out-dated approaches that attempt to avoid the build up of close social contacts between the disabled and those who assist them.

Marinker (1974) has recently described how medical education may emotionally isolate doctors from their patients and 'dehumanise' their relationships. Such dangers exist in all areas of care for the long-term sick or disabled, particularly where professional or occupational groups are pressing for a more secure position in society through the establishment of formalised codes and standards of practice. A greater awareness that the emotional and strategic approach to the major health problems of the late twentieth century must differ radically from that appropriate to the 'crisis' type treatment of a century ago would be of value not only to the medical profession but to all caring agencies. The implicit model of 'professional/client' relationship still adopted by many paramedical and social workers owes its origin, in the main, to the traditional image of 'doctor/patient' interaction.

## Social and economic aspects

During recent years there has been a growing awareness of the problems of the disabled, the chronically sick and the elderly in our society. Results of this trend have included the introduction of the Chronically Sick and Disabled Persons Act, grants such as the attendance allowances now available and the appointment of a Minister for the Disabled.

All these innovations are indicative of a desirable concern regarding the issues surrounding long-term ill health. However, a stage may now have been reached where, before very much larger investments in alternative improvements in care are introduced, there should be rigorous re-evaluation of present health and social services in this area coupled with a detailed study of the feasible long-term objectives of such provisions. As has been argued by Klein and Hall (1974), overviews of the entire pattern of care are



essential for such an evaluation. Despite steps such as the recent DHSS decision to extend the Hospital Advisory Service's\* sphere of interest to include aspects of community care, including some local authority services, there is still no body designed to watch over the complex, interlocked pattern of medical, social, educational, housing and employment facilities for those suffering from handicapping complaints.

In the case of Parkinson's Disease evidence already exists of the potential value of such an approach. Singer (1972) in an attempt to evaluate the social sequelae and costs of Parkinsonism, characterised them as promoting premature social ageing. Her survey, based on a sample drawn throughout the United States, noted falls in occupational activity and income of those affected and decreased ability in the sphere of independent household management combined with heavy reliance on passive leisure activities such as television viewing. More importantly, perhaps, it also indicated a very marked fall in the number of close friendships enjoyed by sufferers of Parkinsonism. Whilst four-fifths of an average population aged between 62 and 74 years reported having four or more good friends, only about half of those with Parkinson's Disease did so. Singer's work also showed that amongst younger people suffering disablement due to Parkinson's Disease distress was more acute than amongst older people, probably because their expectations in life were greater.

The point to be drawn here is that the primary need of patients, apart from specific medical treatments, is for care designed to help them to lead as full a life as possible despite their illness. Unfortunately the prevailing attitude characterising care for the chronically sick is often at present still that, like the acutely ill, they need protection from the stresses of everyday life rather than encouragement to face them. Thus an inappropriate pattern of treatment emerges.

Even with conditions which can have such serious physical effects only a tiny minority of patients are beyond the point of benefiting from active involvement in the life of the world around them. With illnesses affecting elderly people in particular it may often be that physical and mental degeneration taken to be an inevitable aspect of the disease they suffer from is in fact a result of isolation, inactivity and despair. In the case of Parkinsonism it is certain that much of the mental distress suffered by patients could be reduced by improved social conditions, despite the endogenous aspects of mental disturbance associated with the condition.

Thus future planning of services must increasingly take into account sociological and psychological aspects of health. This at

\*Primarily concerned with the mentally ill and aspects of geriatric care. Now known as the Health Advisory Service.

present is not achieved, not least because many current projects in, for example, the field of medical sociology appear ill-conceived. There is a tendency for them to concentrate too much on the relations surrounding the professional services and to neglect attempts at defining the elements within people's lives which are fundamentally responsible for generating a subjective experience of health and wellbeing. The influence of other disciplines, such as economics and medicine itself may lead social researchers to over-concentrate on simplistic quantitative analyses of events and ignore more difficult qualitative examinations likely to be of more value to those receiving care than those providing it.

It is to be hoped that evaluative bias of this nature can be avoided in the future. If not then it is probable that a pattern of increased medical and social service spending stimulated by demands stemming from personal and social needs which care of the type provided cannot satisfy will emerge. This could be at the cost of retarding more desirable growth in other sectors of society and the economy. For example, it may be that within the present system there are areas where the need for personal choice as opposed to professional direction is underestimated. The discretionary income of disabled individuals is thus left very low whilst increasing resources are channelled towards the support of caring services. And the potential industrial productivity of people providing the latter is lost to the community.

### The costs of care

Attempts to express the overall costs of a disease, either to a society or to an individual, can be highly misleading. Indicators such as lost national or personal income or years of productive activity may tend to over-estimate the significance of diseases which affect mainly

**Table 2** *Cost of Parkinson's Disease to the NHS: year 1972*

	£	T	% of T
Hospital In-patient Cost (current)	9.3	1,600 (c)	0.58
General medical services	0.6	215	0.28
Pharmaceutical services	3.1	264	1.17
Dental and ophthalmic	—	166	—
<b>Total</b>	<b>13</b>	<b>2,245</b>	<b>0.57</b>
Other health expenditure	NA	487	

Source OHE Estimates

Note Capital charges associated with the in-patient care of patients with Parkinson's Disease are estimated at £2 million per annum.



those of working age and under-estimate that of conditions such as Parkinsonism which occur chiefly amongst elderly people.

However, it may be estimated that the treatment of those with Parkinson's Disease cost the NHS approximately £15 million in 1972, the largest proportion of this sum being accounted for by the estimated expenditure on long-term hospital care for severely disabled patients (see Table 2). Although this figure gives little indication of the degree of distress generated by such illness it underlines the potential value of treatment, especially that which prevents the onset of handicap and the loss of personal independence.

It therefore appears that research expenditure such as that incurred by the pharmaceutical industry in fields such as developing drugs effective in alleviating Parkinsonism has a high yield for society as compared with expenditure on new products in other areas of manufacturing or service industry. Although cost-benefit analysis of new medicines such as L-dopa must be treated with great caution if only because of limited knowledge about their long-term clinical value, it is clear that their contribution to individual and community wellbeing is immense and can, potentially at least, be quantified far more accurately than can, say, the value of expenditure on social care. A comparatively recent Swiss estimate suggests that each patient responding to L-dopa may be given, on average, about six years more independent, although not symptom free, life than could be expected otherwise (Brungger 1972).

In this context the formation of the Parkinson's Disease Society is to be welcomed. Despite the current economic problems facing nearly all charities it hopes to be able to devote significant funds to the investigation of this malady as well as providing a personal service of value to individual sufferers.

## Conclusion

Although it is still an unpleasant and incurable condition improvements in the treatment of Parkinson's Disease, stemming mainly from the introduction of L-dopa for therapeutic use some seven years ago, enable most people who develop the condition to lead a fuller life than was possible in the past. Further research may soon lead to refinements in the medicines available although a fundamental understanding of the basic causes of physiological changes involved in the disease will probably be needed before any major advances in therapy will occur. It is likely, however, that at some time in the future methods of preventing the symptomatic appearance and long-term progression of Parkinsonism will be developed.

Yet even within the confines of present-day health care technology a considerable alleviation of the situation of those suffering from



Parkinson's Disease may be possible. A fuller integration of health and social care services could improve the efficacy of both. And health education designed to inform individuals in the early stages of Parkinsonism of the disabilities they may expect to face and to help them build realistic expectations in life could prove valuable, particularly if through it they could meet people with difficulties similar to their own.

The sharing of mutual experiences through membership of an organisation such as the Parkinson's Disease Society may also help both those affected by Parkinsonism and their relatives to find solutions to many of their problems and to break down their sense of social isolation.

Thus, despite their immense contribution in recent years, the value of presently available medicines in the treatment of Parkinson's Disease should not be allowed to obscure the importance of other potentially therapeutic factors. As Oliver Sacks described in his book *Awakenings*, which detailed the early and all too often short-lived improvement of long-term Parkinson sufferers (mainly post-encephalitic) treated with L-dopa, recovery very often depends on the nature of the world a sick person is encouraged to rejoin. In a loving and supportive atmosphere patients have a far greater chance of regaining and retaining degrees of physical health than in cases where their future prospects hold less chance of the warmth of human community.

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