MOTOR NEURONE DISEASE

Supporting patients and their families

by PAMELA EMY

Public awareness of Motor Neurone Disease—also referred to as Amyotrophic Lateral Sclerosis (ALS), progressive muscular atrophy, or bulbar palsy—was heightened recently by the death from the disease of David Niven. Its distressing aspects are described below.

Pamela Emy is one of the Association's three Patient Care Officers, and covers London and the south of England. As a former medical social worker, she has had long experience in the field of statutory social services, particularly related to illness and physical handicap. She or her colleagues would be happy to hear from anyone seeking information about the illness, and of means of helping.

Motor Neurone Disease is an illness little known outside the families of sufferers. It leads to the death of some 600-700 people a year in England and Wales. The cause is unknown and no treatment can be offered apart from some palliative measures. Those bereaved express overriding feelings of frustration and helplessness at having been powerless to do anything as they watch a loved one "waste away".

Motor Neurone Disease (often shorted to MND and known in some countries as Amyotrophic Lateral Sclerosis—ALS) is a progressive and seriously disabling disease of the central nervous system. Nerve cells in the brain and spinal cord are slowly destroyed, leading to progressive weakness and wasting of the muscles. This may affect initially a hand or arm, or alternatively the leg muscles, often with spasticity. Some patients—indeed most in the later stages—are affected by bulbar palsy causing difficulties with breathing, speech and swallowing. Progress of the disease is often rapid and may lead to complete immobility and loss of speech. The disease does not affect the sensory system, nor, most importantly, is the brain or intellect affected in any way. Although in a proportion of patients the disease may "plateau", for most it moves inexorably downhill, death occurring within 2-5 years of diagnosis, sometimes sooner, and its course is devastating not only for patients and families, but also for those attending them.

Those affected are most commonly in their 50s and 60s but onset at a younger age is not unusual. There are about 5,000 patients in the United Kingdom.

Patients and families need help and support throughout the illness. Much can be done to maintain the patient's independence and dignity and alleviate distress by the speedy provision of appropriate aids and equipment, but continual surveillance and reassessment is necessary as needs will constantly change. Equally important is ongoing support and counselling, with opportunities for discussion of problems and anxieties, and assistance with planning for what lies ahead.

As the disease progresses heavy demands, both physical and emotional, are made on the carers as patients become increasingly helpless and unable to carry out even the simplest activity for themselves. Personal attendance is needed throughout the day—and in the later stages at night too, leading to broken sleep and exhaustion. Swallowing difficulties may necessitate spoonfeeding, with mealtimes becoming increasingly time-consuming.

Amazing strength and courage is shown by husbands and wives caring for spouses in this way; for those without a partner difficulties are accentuated. Most families wish and endeavour to keep the sick person in his own home, where interests can be maintained in familiar surroundings. Additional help, ideally of the "care attendant" type, is invaluable to provide some respite for the carer, or short term residential care may be arranged. Some patients must inevitably look to longer term in-patient care and vacancies may be sought in acute or geriatric hospital wards, young disabled units, or, perhaps ideally, in hospices. Local provision varies considerably; the search for an appropriate bed may cause further distress to families.

Death most commonly results from a respiratory infection with which the weakened body is unable to deal, sometimes necessitating a brief period in hospital, even for patients otherwise nursed at home. Although the family is already facing the knowledge of a terminal illness, the end may in fact come suddenly and unexpectedly.

Two aspects of the illness may cause particular burden and heartache to the spouse. The first, common to many chronic or terminal illnesses, is what should the



patient be told. Sometimes only the spouse is advised of the seriousness of the illness, and must decide how much information should be conveyed to the patient. A sharing of knowledge between patient and carer may enable a couple to use positively and to the full the time that remains for them together. Secondly, loss of speech, an all too familiar aspect of the disease, leads to a complete breakdown in normal communication, making it increasingly difficult to involve the patient in decisions closely affecting his care. Early discussion, while speech remains, is of great importance. In spite of the development of an increasing number of mechanical communication aids, nothing can totally replace normal speech.

The course of the disease described above may serve to give

some indication of the feelings and emotions of those eventually bereaved by this distressing condition, in addition to those commonly experienced following any long term illness. Most families will not have heard of the disease prior to the diagnosis and will have suffered consequent feelings of isolation. The precise pattern of the disease varies from individual to individual. For some, its very rapidity may have hardly allowed families to absorb what was happening. For others the terminal stages may have been long drawn out, involving increasing exhaustion of the carer, or the distress of daily visits to home, hospice or hospital. Distress is accentuated when normal communication has been interrupted. The absence, normally, of personality change in the patient may mean that the carer has undergone little preparatory mourning. Frustrations may have arisen over the provision of practical help, with equipment arriving "too late" to be of assistance. There may be regret or guilt that knowledge of the illness has not been more fully shared. And perhaps overall are the feelings of anger and frustration at being involved in an illness about which so little is known and in which research so far seems unproductive.

The Motor Neurone Disease Association was formed in 1979 by a group of patients and families both to support research, and to provide information, advice and support to sufferers. Currently directed from its headquarters in Northampton, it is developing a local branch structure with informed volunteers who can maintain personal contact with patients and families. Most of those active in the Association have had personal experience of the disease. Many bereaved, after surmounting their initial grief and mourning, do find solace in some personal involvement in the Association's activities. The Association employs three Patient Care Officers with an educational and consultative role in relation to both patients and professional workers. They are available to give help and advice to individual patients and mobilise help on their behalf.

Much work lies ahead before the cause of and cure for this tragic illness can be found. Meanwhile more widespread knowledge and understanding of the disease and its problems will help to improve the quality of life remaining to those who suffer.

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Abroad: are there equivalents to Cruse?

We know of organisations to help widows in many countries; a good many are listed in the Appendix to Mrs. Torrie's book **Begin Again,** though that list is several years old now, and inevitably no longer quite accurate. Some of the groups are for widowers also, but not all. In general they are run by widowed people. The mix of widowed and non-widowed, professional, semi-professional and volunteer seems to be more or less unique to Cruse. There do seem to be very few organisations that also comprehend other kinds of bereavement, either separately or together with that of widowhood.

How do they help, these organisations? **The Australian Association of Civilian Widows** has the motto "Friendship & Service". There are several branches that obviously give warm understanding to new members, and new social opportunities. Throughout their 25 year history (one year ahead of us), the Association has chipped away at social prejudices against widows, and worked to alleviate their financial position.

In the United States there is no organisation covering every state, though the **National Association for Widowed People** does have regional offices in 21 states, and two places in Canada. Their headquarters is at: PO Box 3564, Springfield, Illinois, IL 62708. They charge $35.00 a year for membership, and $1,000 for life membership, but for that you get quite a few benefits, like eligibility for cheaper group health insurance plans, and a beautiful glossy quarterly journal. The organisation undertakes counselling and runs social events (both presumably from the regional centres), and lobbies on behalf of widowed people. There are also professional counselling services in several centres, and numbers of self-help groups called **"Widow-to-Widow Programs".**

From South Africa Cruse House receives the newsletter of the **Widows' Information Service.** The Service is involved with the newish Women's Bureau, which has a working group on widows. The Information Service runs social activities in Cape Town, and hopes to start branches in Johannesburg, Durban and East London. Their latest news'etter covers a booklet on bereavement, help with accommodation and pensions, and short feature pieces.

In Europe seven national associations of widowed people from four countries are now associated in the executive of an international group called **The International Federation of Widow and Widower Organisations.** (The initials FIAV come from that name in French). FIAV has also member organisations from Australia, Haute Volta, New Zealand, Norway, South Africa and the United States. Derek Nuttall represents Cruse on the Executive, which meets once or twice a year. There are obviously differences of emphasis—all the other organisations on the executive are run on a self-help basis by widows and widowers, and none seem to have anything quite like our trained counsellors in each branch. There are also some Roman Catholic national organisations of widowed people who meet together in another international group occasionally.

All the time we do hear about local groups, in many countries. They are either self-help groups or bereavement counselling organisations. Many widows and widowers also derive much support and help from sing'es groups that are not exclusive to bereaved people.

There are two organisations in the Republic of Ire'and: **The National Associations of Widows,** and **The Widowed Persons' Association,** which started as a widowers' self-help group. These latter produced their first newsletter recently.

DEATH & IMMORTALITY: UNIVERSITY COURSE

A unique, taught, MA course started at St. David's University College, Lampeter, Wales, in October. Staff from six departments are now pooling their resources to produce a new postgraduate degree in *Death and Immortality in Western Th·ught.* Students firstly examine the arguments for and against belief in a future life in a compulsory core course and then pursue three out of a list of eight options. Half the options are in the area of religious thought, and look at the beliefs of Ancient Greece and Rome, Biblical ideas about the nature and destiny of man, the concept of the soul in Western philosophy, and the doctrines of resurrection, immortality, heaven and hell in Christian doctrine. There are four literary options looking at the theme of death and immortality in European literature from the fourth century onwards. Of the lecturers responsible for the course, eight are from the departments of Theology, Philosophy and Classics, and eight from the departments of English, French and German.

It is hoped that the course will appeal to students of theology, philosophy and literature who will be able to develop their studies through focusing on a theme which has been of crucial importance to Western thought and in which interest has been reawakened in recent times through the apparent evidence suggestive of a future life through the near-death experiences of resuscitated persons.