Standards of Care for People with Disabling (Progressive and Static) Neurological Conditions in the Hospital and Community
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Neurological conditions are common, affecting over 500,000 people in the Irish population. Recent advances in the Neurosciences have improved the outlook for many neurological conditions, as major breakthroughs have been achieved in understanding disease pathogenesis, creating for the first time the prospect of symptom arrest, and eventually cure of the disease process. However at present, most neurological conditions remain incurable and treatment is often symptomatic or at best partially effective.

Most neurological conditions are chronic, requiring input of care across a vast range of health, social and other services. This reflects the fact that these conditions have a wide-ranging, variable and complex set of physical and psychosocial problems requiring specialist expertise both for recognition and treatment. The needs span a wide range of services that are not traditionally well-integrated, including hospital and community-based health services, employment, legal and social services.

At present, resources devoted to treatment and community care are limited and can vary greatly between hospital and health board according to priorities and levels of funding. The challenge is to develop an integrated, co-ordinated and predictable health and social welfare facility that is geared towards the particular needs of the individual.

With this in mind, the Irish Neurological Alliance (the national alliance of 18 neurological charities) and a multidisciplinary group under the umbrella of the Elan Neurology Advisory Board, have come together to examine what Standards of Care (SOC) should be in existence for three categories of neurological conditions and should be offered to people with neurological conditions and to their families. These are disabling neurological conditions, non-physically (chronic) disabling neurological conditions and neurological conditions where cognitive decline is a major feature.

This document describes SOC that should be in place for those with disabling (progressive and static) neurological conditions. The other SOC will be addressed at a later date.

As a group, we believe that by drafting and promoting these SOC, we are serving three basic but vital needs for providers and users of health related services.

These are as follows:
• increasing understanding of the issues involved with respect to the care of people with neurological conditions in the hospital and community

• setting benchmarks for purchasers and providers of these services so that resources are being offered and utilised for their optimum effectiveness

• guiding health professionals in providing an equitable and effective service to people with neurological conditions.

Signed (after extensive consultation with all members of the Irish Neurological Alliance)

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Chairperson, Irish Neurological Alliance
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THIS STANDARDS OF CARE DOCUMENT IS THE FIRST IN A SERIES OF THREE STANDARDS OF CARE DOCUMENTS. THESE ARE AS FOLLOWS:

(I) Standards of Care for People with Disabling Neurological Conditions (Progressive and Static)

(A) Progressive Disabling Neurological Conditions

Conditions
- Alzheimer’s Disease
- Certain Brain Injuries
- Dementia (Non-Alzheimer)
- Dystonia
- Friedreich’s Ataxia
- Huntington’s Disease
- Motor Neurone Disease
- Multiple Sclerosis
- Muscular Dystrophy
- Myasthenia Gravis
- Neurofibromatosis
- Parkinson’s Disease
- Post Polio Syndrome
- Spinal Cord Injury
- Syringomyelia

Relevant Patient Support Groups
- Alzheimer Society of Ireland
- Dystonia Ireland
- Frederick’s Ataxia Society of Ireland
- Headway Ireland
- Huntington’s Disease Association of Ireland
- Irish Brain Research Foundation
- Irish Motor Neurone Disease Association
- Multiple Sclerosis Society of Ireland
- Muscular Dystrophy Ireland
- Myasthenia Gravis Association
- Neurofibromatosis Association
- Parkinson’s Association of Ireland
- Post Polio Support Group
- Spinal Cord Injuries Action Association
- Syringomyelia Self Help Group

(B) Static Disabling Neurological Conditions

Conditions
- Cerebral Palsy
- Dyspraxia
- Head Injury (which can be progressive)
- Neuropsychiatric conditions
- Old Polio
- Some forms of Epilepsy
- Spina Bifida and Hydrocephalus (which can be progressive)
- Spinal Cord Injury
- Stroke
Relevant Patient Support Groups

- Brainwave - Irish Epilepsy Association
- Cerebral Palsy Ireland
- Dyspraxia Association
- Headway
- Irish Association for Spina Bifida and Hydrocephalus
- Post Polio Support Group
- Spinal Cord Injuries Action Association
- Volunteer Stroke Scheme

(II) Standards of Care for People with Non-Physically (Chronic) Disabling Neurological Conditions

Conditions

- Epilepsy
- Migraine
- Autism
- Schizophrenia

Relevant Patient Support Groups

- Brainwave - Irish Epilepsy Association
- Irish Migraine Association
- Irish Society for Autism
- Schizophrenia Ireland

(III) Additional Features of Standards of Care for People with Disabling Neurological Conditions where Cognitive Decline is a Major Feature

Conditions

- Alzheimer’s Disease
- Dementia (Non-Alzheimer)
- Huntington’s Disease
- Parkinson’s Disease
- Traumatic Brain Injuries

Relevant Patient Support Groups

- Alzheimer Society
- Headway
- Huntington’s Disease Association of Ireland
- Parkinson’s Association of Ireland
For practical purposes in drafting these Standards of Care for People with Disabling Neurological Conditions (progressive and static), we have considered four phases of the neurological condition and some other important issues with regard to the care of these people and their families and the attitude of society towards them:

Section I  The Diagnostic Phase
Section II  The Minimal Impairment Phase
Section III The Moderate Disability Phase
Section IV  The Significant Disability Phase
Section V  Family/Carer Section
Section VI  Stigma and Neurological Conditions
Section VII Access to Different Modes of Transport
Section VIII Predictive Testing in Inherited Neurological Conditions

In considering staging of neurological conditions, we fully recognise that not all these stages are relevant to all types of disabling neurological conditions and when a person is going through these stages, their needs may span several categories, vary over time, or remain stable.

An individual may require some or all of the recommended standards described in each of the four sections of the document. At all stages the individual’s needs must be considered, as each person’s experience is unique.

It is also worth noting that whilst some conditions may not be progressive, as children mature the challenges presented by their condition may become more acute due to their lower rate of physical learning when compared to their peers.

In compiling these SOC and in line with the different phases of a neurological condition, we have tried to promote five crucial messages:

- Information needs to be presented in a user-friendly form
- Providers of services to people with neurological conditions need to show sensitivity and support
- Care needs to be continuous
- Services need to be easily accessible through a central point of contact
- Appropriate voluntary organisations and patient support groups need to be easily accessible

In the compilation of this document, we have referred to people as ‘people’ when we discuss certain medical situations and have used terminology such as ‘people affected by’ or ‘service user’ when describing other circumstances.
Section I

The Diagnostic Phase
Introduction

This is a particularly important time for any person with a neurological condition. If this phase is not managed properly and the person does not receive information in a supportive, skilled environment, it can have negative long-term effects for the individual and his/her family.

Recommended Standards for a Certain, Clear Diagnosis

All people have the right to expect that any medical condition will be efficiently investigated and diagnosed. Most people will initiate the process of establishing a diagnosis through their GP at the onset of symptoms.

Stroke, which affects 8,000 people in Ireland, is an acute medical emergency which requires immediate referral to specialist services, ideally in an acute stroke service. All patients with stroke should be under the care of an interdisciplinary team led by a physician with specialist training in stroke, in the setting of a stroke unit within a clearly defined continuum of care.

For some people, especially those with rare neurological illness, it may take a little time for these to be recognised as such, especially in the early stages. This can be an anxious and frustrating time for the patient as well as the GP. This is further exacerbated by the poor availability of neurological services in certain areas.

Referral to a Consultant

• In anticipation of a correct and speedy diagnosis, a prompt referral to neurologist or geriatrician (or other specialist where appropriate) is required, followed by appropriate investigation and feedback. Referral time should be short – the ideal should be four weeks from the referral by a GP to being seen by a consultant. This however is not always the case because neurology services are poorly available.

• It would be useful if neurology clinics operated a ‘fast tracking mechanism’ whereby a ‘concerned GP’ could easily contact the consultant, voice his concerns and obtain some management options to tide him over while the patient waits to be seen at the next available clinic.

• When a person is referred, there may still be a period before a definitive diagnosis can be made. Sometimes this is because the situation is not clear-cut and sometimes because the initial referral proved to be inappropriate.

Clinical Investigations

• Ideally, investigations should be completed as quickly as possible after the initial consultation with the neurologist, or within a maximum period of one month.

• The results of investigations should be communicated to the person with the neurological condition within two to four weeks of their completion.

Recommended Standards for Appropriate Support at Diagnosis

Diagnosis is a particularly difficult and stressful time especially for people (or children and their parents) who have experienced confusing and distressing symptoms of a neurological condition over a long period of time.
Imparting and Receiving Information on Diagnosis

- Information about a diagnosis should be presented by a neurologist or geriatrician (or other specialist where appropriate).

- Information should be presented carefully and slowly, taking into account the often-limited ability of the individual to take in information immediately following diagnosis. This will help in developing a realistic approach to the condition.

- The consultant should explain to the person with the condition the process of diagnosis, including the range of tests to be carried out and the time it is expected to take. At this stage it would be desirable if the consultant took some time to assess the person’s understanding of the diagnosis.

- The person with the condition has a right to know the diagnosis, should always learn about his/ her diagnosis first and has the right to be accompanied by a family member. The diagnosis should then be shared as soon as possible with the person’s partner/ family/ carer and with his or her consent. Discussion of the diagnosis should be undertaken only at a time when the person with the condition has immediate access to a family member or close friend.

- The process of breaking the news of a specific diagnosis should be undertaken with sensitivity. If this occurs in a hospital setting, it should take place in the presence of a member of the house staff and nursing staff with whom the person has developed a relationship. Adequate time should be provided to enable the person and/or family member to ask questions about the diagnosis, treatment options and prognosis.

- In the case where a child is being diagnosed with the condition, the parent or guardian has a right to learn of the diagnosis in the first instance.

- The newly diagnosed person or his parent(s) has the right to request a second opinion from another neurologist or geriatrician (or other specialist where appropriate) without prejudice to his/ her rights and has a right to look at his/her hospital records.

The Relevant Voluntary Support Organisation

- Everything possible should be done to meet information needs and the name and address of the appropriate voluntary/ support organisation should be given at the time of diagnosis.

- In progressive disabling neurological conditions, relaying knowledge about the disease process needs to be done in a structured, amenable way and it might benefit certain people for them to meet others who are going through similar situations. Ideally, such meetings should be facilitated by the local patient support group and the local neurologist, geriatrician (or other specialist where appropriate) and/or practice nurse or specialist nurse.

Legal and Entitlement Advice

- Persons with a newly diagnosed neurological condition should be informed by a social worker if possible as to the likely impact of their condition with respect to work or school/university etc, and should be directed towards an appropriate advisory body (provided by voluntary organisations, citizens rights bureau, trade union etc.). Those individuals entitled to services through the long-term condition and disability scheme should be informed of their entitlement.

- Any potential insurance implications of the condition should be clearly identified and discussed.
Discharge Planning

- A clear and established protocol should enable the person to be referred back to the GP (or another specialist e.g. Occupational Therapist/ Speech Therapist) with written confirmation of the diagnosis and/ or the consultant’s conclusions as soon as possible. Where necessary, and particularly in rare conditions, an information package should be made available to the GP, the patient and his family with details of the diagnosis, treatment options and information regarding the appropriate voluntary organisation.

- In this protocol, a treatment/ management plan should be included outlining the responsibilities of the consultant, the GP and the community services already involved. This should suggest how the continued surveillance and management of the affected person should be undertaken. This will ensure that support is available to individuals and their families from the onset of symptoms, through diagnosis and thereafter.

- A nurse or other support worker – ideally with specialist knowledge of neurological conditions and counselling experience – should be available in the weeks following diagnosis to provide information and support. Referral to expert counselling should also be available.

- A further appointment with the neurologist, geriatrician (or other specialist where appropriate) should be arranged to discuss technical or medical questions that might arise.

- Following diagnosis and in line with the treatment/ management plan drawn up at the diagnostic phase, people with neurological conditions should be put in contact with a specialist multidisciplinary team in their area. Ideally, this team would include a neurologist or rehabilitation specialist, and support worker and specialist nurse. This multidisciplinary team should then provide a focal point for appropriate information, guidance, basic treatment and management and more specialist referral if required. It should be noted however that there are regions in Ireland that are not adequately serviced by neurologist or geriatrician (or other specialist where appropriate). In the case of rare conditions, facilities should be put in place to enable those with the condition to travel to a specialist clinic if one is available, and if they wish to do so.

- At present such teams are not available across the country and as such these recommendations are purely aspirational. For further information on recommendations with regard to the number of Neurologists, Rehabilitation Specialists and Geriatricians in Ireland, please see Appendices B, C and D.
Section II

The Minimal Impairment Phase
Introduction

This phase refers to the post-diagnostic period when input from certain healthcare professionals, especially the General Practitioner and associated community services, is crucial.

The implementation of therapy, social support and appropriate medication (which may not be appropriate in all cases), lays down the foundation on which long-term management and service input can be built. Such service input needs to be integrated with extensive communication and liaison between key providers with an emphasis on availability, adequacy and flexibility.

In the case of a neurological condition which is progressive, many people may experience long periods of minimal impairment throughout the course of their disease, but still need statutory and health service provision. In the case of static or non-disabling neurological conditions, many people will also go through the minimal impairment phase.

Recommended Standards for Support and Informed Advice

Employment

- Employment is a major issue for people with neurological conditions. In disabling neurological conditions it is essential that people continue working for as long as possible to maintain their self-esteem and financial stability and that employers are given accurate information and advice on the needs of these employees and are encouraged to be flexible and offer altered working hours or responsibilities where required.

- Facilities should also be put in place within the community in this regard. For example, those with impairment that requires the use of a car to enable them to continue to work should be eligible for a disability-related tax exemption in the purchase of an appropriately adapted car (Please see Appendix E).

Re-Training and Education


- Participating in mainstream education may be very difficult for children with some neurological conditions and in this regard, the support of a classroom assistant is vital.

Financial Planning

- Financial planning is important and often hindered by the lack of advice and information about social security benefits, insurance, and employment. Not knowing the long-term prognosis makes it difficult for people with progressive disability to plan or foresee their future needs. This adds to the distress and confusion that they may experience throughout the course of their condition.

Citizens Advice

- Housing presents problems if the prospect of reduced earnings and increasing disability and dependence seems likely. People with disabling neurological conditions also need access to up-to-date advice on work-related issues, resources for adaptations, pension, insurance rights, income, mortgages etc. Some of these services can be provided locally through Citizens Information Centres (CICs) or through the appropriate support group network.
Recommended Standards for Access to Treatment for Conditions Unrelated to the Primary Neurological Condition

Conditions unrelated to the primary neurological condition often remain undetected due to inexperience and/or ignorance about symptoms and the effects of the condition. This can lead to unnecessary complications and sometimes protracted discomfort and pain.

General Practitioner Expertise and Input

- In consultation with the General Practitioner Continuing Medical Education (CME) network of the Irish College of General Practitioners and its national director, the Irish Neurological Alliance undertakes to identify areas where the knowledge and skills base of certain common disabling neurological conditions should be broadened. The Alliance also undertakes to set up some form of helpline/website or information pack where General Practitioners can readily access information regarding important advances in these areas.

- As with any chronic medical condition, regular assessment and review should be carried out by the GP taking physical, physiological and social factors into account. The frequency of these assessments will depend on the patient, his illness, social factors such as the availability of carers and the coping skills that he/she possesses. These assessments will consider not just the neurological situation, but will also look at the whole patient for evidence of any other intercurrent medical condition such as chest or urinary infection. Appropriate arrangements for referral and follow-up will be made.

Specialist Expertise and Input

- Where a genetic disorder is present, the neurologist/geneticist should inform the family member of the implications of the disorder.

- It is essential that the neurologist reviews each case on a regular basis especially in the case of rare genetic illness and the new and relevant information should be provided to families where appropriate.
Section III

The Moderate Disability Phase
Introduction

In disabling neurological conditions, the Moderate Disability Phase concentrates on symptomatic management and neuro-rehabilitation. In this phase of the disease, progression symptoms may be many, varied and interrelated. Management of these symptoms can therefore be challenging. Management usually requires an integrated multidisciplinary approach to provide a focused neuro-rehabilitation service, which aims to reduce disability and handicap and improve quality of life.

Recommended Standards to make Services Responsive

Services are not always accessible at the time of need for people who are experiencing a worsening of their symptoms or a significant change in their level of functioning (e.g. using a wheelchair for the first time). Some people experience a waiting time of up to 12 months from the onset of a new problem.

Emphasis on Fast-track Approach

• All services should be flexible and responsive to the needs as defined by the person with the neurological condition. A “fast track” system should be available to access resources, including neurological review, equipment modification and increased levels of care.

Hospital and Community Co-operation

• At the moderate disability phase of a neurological condition the person might encounter as many as 30 different health and social services professionals. Co-ordination of service provision between these professionals is paramount.

• There should be clear links between the local social and health services and the multidisciplinary neurology service, both in-person and out-person, allowing cross referral in a responsive and timely fashion. The details of these should be communicated to everyone including local support groups, people with neurological conditions and their carers. People need to know which services require a General Practitioner, a neurologist, geriatrician (or other specialist where appropriate) or self-referral. They also need to know that there is a team approach to their care.

• Sound, practical information for the management of neurological condition needs to be disseminated from specialist professionals to non-specialist colleagues, carers or other agencies in a systematic way.

• Neurologists, geriatricians (or other specialists where appropriate) should act as education and training consultants in order to maximise professional expertise and should use opportunities to disseminate specialist information through publications and conferences.

• When different health and social services professionals plan care, it is preferable that one named person acts as a bridge between primary and secondary care, health and social services and other care agencies. In some cases this role is best served by a Practice Nurse or Specialist Nurse who can spend time in the person’s home explaining the assessment and care plan (which should include the names of relevant professionals) and the various recommendations that have been made by different professionals.

• Where co-ordination is not taking place people should be provided with the information and support to enable them to make a complaint or to challenge the provision of care.
Complaints

- A person has the right to complain about any aspect of hospital or healthcare service, to have the complaint investigated, and to be informed of the outcome as soon as possible.

- Each hospital should have detailed complaint procedures in place and should publicise these prominently throughout the hospital, together with the name and telephone number of the hospital’s designated Complaints Officer, (Ref.: Charter of Rights for Hospital Patients, 1992). A person has the right, where the complaint is not resolved to their satisfaction, to have the matter referred to the hospital’s Complaints Committee.

- The hospitals’ complaints procedures are without prejudice to a person’s statutory rights to also complain to the Ombudsman, the Medical Council or An Bord Altranais (The Nursing Board).

Service and Equipment Provision

- Service and equipment provision should reflect the shift towards community care, enabling rehabilitation to take place in the home where appropriate but in-patient facilities should be also widely available.

- In the community setting, a person with a neurological condition who has a Medical Card or is on the Long Term Illness Scheme can apply for appliances (mobility aids/ special footwear/ wheelchairs/ special seating/ bathing aids etc.) through the Appliance Officer at their local Health Board. The Community Physiotherapist or Occupational Therapist will investigate the application and if it is approved will order the appliance.

- For those who are eligible for a grant aid from the Disabled Persons Housing Grant Scheme, it is recommended that this grant is commensurate with the real cost of living.

Recommended Standards to make Services more User Friendly

People with a disabling neurological condition currently have no influence in the purchasing process and therefore no influence on the services that are available to them. Specifications on the various services required should be made available to people on what constitutes a good quality, value-for-money service. These should be developed in consultation with local support groups.

Specification on Services

- People with disabling neurological conditions and their families will then be able to make informed decisions about the treatment and management of their disease and their lifestyle.
Section IV

The Significant Disability Phase
**The Significant Disability Phase**

*Introduction*

This is the stage where the person with a disabling neurological condition often has a wide range of complex and interacting physical, psychosocial, and cognitive problems. During this phase many people are heavily reliant on others so that they can maintain as good a quality of life as possible. The level of support and expertise provided by the carer is paramount. Frequently the degree of this support is the determining factor in deciding whether the person remains at home or requires long-term residential accommodation.

*Recommended Standards for Provision of Respite Care*

Caring for a significantly disabled person can be extremely demanding, both physically and emotionally and there often comes a time when long-term or respite residential accommodation become a requisite.

It is however often the case that respite care facilities are inappropriate, too costly or unavailable on a regular basis. Long waiting lists are also common place following assessment for respite care.

*Information on Suitable Facilities*

- People with disabling neurological conditions and their carers need information on respite, long-term and palliative care facilities, day centres and community care resources so that they can make informed decisions. This information should be easily accessible, timely, accurate and available as an up-to-date and understandable resource. It should also be available in printed form, on the Internet and via telephone helpline.

- Regular and varying (e.g. respite and palliative) care facilities, in an appropriate setting which provide a good quality of life, should be available when required and people and their carers should be directly involved in the choice of same.

- In long-term institutional care, social and healthcare which offers a high degree of stimulation should be provided, not just custodial care.

- Full-time care within the person’s own home should also be available as an option for long-term or respite care.

- All care should be of a high standard and appropriate to the specific needs of both the person with the disabling neurological condition and his or her carer.

- Staff caring for people with disabling neurological conditions should be trained in the physical, cognitive and psychosocial problems which may commonly present or subsequently present in the later stages of the condition.

- People with disabling neurological conditions who are in the later stages of the condition should have access to specialist input in their care when required, whether they are being cared for at home or in long-term institutional care.

*Recommended Standards for Effective Co-ordination of Services*

As in the previous phase of Moderate Disability, people often rely on a wide variety of health and social service professionals to meet their needs. These services often fail to take into account the view points of people and their families, particularly those who are severely disabled and who may no longer be able to speak independently.

Poor communication and co-ordination between healthcare services and social services are common. No clear demarcation of the responsibilities of these two sectors seems to exist and this frequently results in confusion about the delivery of services at local level with no one taking ultimate responsibility for a successful outcome. This is often particularly evident when a person is discharged from hospital into the community.
Need for Client-Centred Plans

- At the Severe Disability Phase, the person with the disabling neurological condition should have a co-ordinated and person-centred management plan at all stages of the care process, co-ordinated by a community care manager, a key worker or outreach specialist, neurology nurse or support worker. Roles should be clearly defined so that healthcare purchasers, providers and users are able to understand the responsibilities of each of these services.

Recommended Standards for Adequate Community Care Services

Following community care assessments, people commonly experience long waiting times. This often means that the equipment and services that were recommended at a particular point in time are inappropriate by the time they are available; or that unnecessary secondary complications, or frustration and anxiety may be experienced in the interim.

Environmental barriers to health and social services facilities, such as GP surgeries, dentists, day centres and hospitals, frequently prevent the severely disabled person from gaining access to these services. As a consequence, general medical tests and treatments such as cervical smears, dental care, and dietary advice are often not available.

Access to Free Healthcare

- General healthcare should be available for everyone on an equal basis but home visits should be provided when access to health or social service centres is limited. It is recommended that home visits already form an integral part of the routine of general practitioner care. On diagnosis, people with a progressive and disabling neurological condition should have an automatic entitlement to a GMS Card (medical card) to enable them to receive all medications free of charge and avail of community healthcare services.

- Adequate, timely and appropriate services need to meet the changing needs of the individual and these should be available on an equitable basis.

- Follow-up services in the community should be available to ensure recommendations are carried out within an appropriate time frame, on return home from hospital or respite care.

Recommended Standards for Improving Community Mobility

Moderate to significantly disabled people are often totally reliant on ambulance or hospital transport to attend appointments, day care centres, respite homes, etc. This transport is often inefficient and unreliable, with excessive delays causing frustration.

- Provision of efficient community transport should be available for significantly disabled people.
Section V

Family/Carer Section
Introduction

Very few Carers plan to take on their role as Carer. Rather, they find themselves in a caring role through life's circumstances.

Many Carers are afraid that they will be frowned upon if they express how lonely or frustrated or tired they feel. Many Carers feel nobody else understands what the life of the Carer is like. However, there are over 100,000 Carers in Ireland, most of whom share the same experiences and feelings.

In considering the role of the Carer, the guiding principle is the need for Carers to remain in control. A vitally important issue is the development of supports which respond to the needs of Carers and which encourage people who do not at present call themselves ‘Carers’ to avail of the supports. It is imperative that these support/ resources both personnel and material are recognised as necessary and rightful. Carers should not be made to feel that they are beggars or unable to cope.

A strong theme continues to be the need for Carers to be involved in the planning and delivery of services to meet their needs given that over 90% of all care in the community is provided by Carers for family members and neighbours.

In the caring role personal relationships with partners, parents and children can be vulnerable, especially when their understanding of the condition and its implications is limited. In the family situation, fear and ignorance, which are often compounded by denial, can lead to communication difficulties and relationship breakdown.

- Parents in a Caring Role

Parents may be faced with a return to a caring role for their adult children with a physically disabling neurological condition.

- Children in a Caring Role

Children of a parent with a disabling neurological condition may also be affected by their lack of knowledge and suitable information about the condition and its effects.

Children with parents whose normal functioning is being impaired by a neurological condition can suffer from severe peer group pressure to have ‘normal’ parents. In this case children can become rebellious or withdrawn, and may have difficulty coping at school. They are also often drawn into providing significant care and support for their debilitated parent often at the expense of usual childhood activities.

Recommended Standards for the Provision of Support and Informed Advice to Families and Carers

Personal Relationships

- In cases when family members are affected and are taking on the role of primary carers, the need for accurate information, support and counselling to help the family understand and respond appropriately is paramount.

Teachers and Schools

- Teachers and schools also need to be made aware of the child’s home situation and responsibilities.
**Recommended Standards to Inform People and their Carers of Self-Management Techniques**

Current service provision tends to treat established problems rather than support people to maintain their health, which means a lack of knowledge amongst people and families about self-management techniques.

People with disabling neurological conditions are reluctant at times to seek advice on potentially embarrassing problems such as urinary, bowel and sexual dysfunction. In these instances they might adopt behavioural patterns which can be detrimental in the longer term and lead to serious intractable problems with, for example, posture or bladder function.

Even when the person is experiencing minimal impairment as a result of their neurological condition, embarrassing problems related to urinary, bowel and sexual dysfunction can also often lead to poor self-esteem, exacerbating relationship difficulties and sexual dysfunction.

**Principles of Management**

- General principles relating, for example, to tone management, posture, fatigue management, continence and appropriate exercise regimes should be made available via the local specialist multidisciplinary teams and local support groups for people experiencing minimal impairment and their families and carers.

- As the urinary, bowel or sexual dysfunction worsens, resulting from the neurological condition, specialist advice on specific treatment should be available from the relevant specialist (e.g. a physiotherapist who specialises in neurology, an occupational therapist, a Practice Nurse or Specialist Nurse, a speech therapist, a dietician or neurologist/rehabilitation specialist) through a simple referral system).

**Advice and Support from Health Professionals**

- GPs and neurologists, geriatricians (or other specialists where appropriate) should be sensitive to the likelihood of these problems, especially problems relating to sexual dysfunction and should use consultations as an opportunity to regularly raise such issues, explore current difficulties and offer suggestions on sources of help, (e.g. continence advice, genito-urinary medicine services, sex and marital psychotherapy and medication).
Recommended Standards for Developing Expertise and Support Structures for Carers

Currently, there is a lack of professional expertise and facilities to address the serious problems experienced by people with advanced neurological conditions, particularly in the area of environmental aids, posture and seating.

The quality of care in health and social services throughout the country, both in the private and public sectors, is variable and sometimes of a poor standard. It is not uncommon for people to develop unnecessary complications, including pressure sores, contractures, urinary and respiratory tract infections both at home and following admission to care facilities.

Family and Person Expertise

• The existing expertise of people and their families in disease management and care should not be underestimated as they have ‘real-life’, long-term and practical experience in coping with the many problems they have encountered.

• Therefore their viewpoints and needs should be integral to the assessment and decision making process with regard to care at the severe disability phase.

Disability Aids

• Regional specialist services for environmental aids and specialist posture and seating should be available to people.

Respite for Carers

There is a chronic lack of respite care facilities in Ireland. Many families need greater support at home and home-based respite care services which suit their family circumstances. Families are faced with a difficult choice when the cared-for person’s care needs are placing a very heavy burden of care on the Carer and the family. The family may be considering residential or nursing home care as a necessary next step but this is often not available.
Section VI

Stigma and Neurological Conditions
Introduction

Being diagnosed with a neurological condition can devastate the life of the affected person and of his/her family. Sometimes the diagnosis is present at birth or shortly afterwards. Sometimes this diagnosis can strike adolescents or young adults disrupting their pursuit of educational and occupational goals and reducing their quality of life.

Neurological conditions are often associated with a significant amount of stigma and discrimination, which further increases the burden on people and their families.

Individuals with neurological conditions often face social isolation, discrimination in housing, education and employment opportunities and other forms of prejudice. The stigma often extends to family members.

The label of a neurological condition can change the perception of observers, it reduces social acceptability and it means that sufferers inhabit a different space in public perception.

It is vital that the concerns of people living with disabling neurological conditions are understood. It is also imperative that misconceptions regarding neurological conditions among the general public and to a lesser degree among health and social care professionals be addressed.

Below is a checklist that outlines some of the misconceptions that exist among people when they come across those with a disabling neurological condition and some of the associated realities.

This resource is intended to help overcome some of the misconceptions that some people with disabling neurological conditions encounter from people they meet and from some of their health and social care professionals.

Misconceptions and Negative Attitudes

<table>
<thead>
<tr>
<th>Misconception</th>
<th>Reality</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with a neurological condition don’t have to be referred to a specialist</td>
<td>A referral to a specialist is required in order to rule out other possible conditions and to ensure appropriate drug treatment is implemented. Regular appointments are necessary to ensure treatment is still appropriate and to monitor the progress of the condition</td>
</tr>
<tr>
<td>Dr. knows best</td>
<td>Not necessarily – decisions should be made in partnership with the person with the neurological condition and as part of a multi-disciplinary team</td>
</tr>
<tr>
<td>The neurological condition is responsible for all health problems</td>
<td>People with neurological conditions are still open to other health problems – it should not be assumed that everything that happens to a person’s health is due to his/her primary condition</td>
</tr>
<tr>
<td>People with neurological conditions are entitled to free prescriptions</td>
<td>Many are not, unless they fulfil low income, age or long-term condition requirements</td>
</tr>
<tr>
<td>Misconception</td>
<td>Neurological conditions are the same from day to day</td>
</tr>
<tr>
<td>---------------</td>
<td>----------------------------------------------------</td>
</tr>
<tr>
<td>Reality</td>
<td>Neurological conditions differ from day to day – even from five minutes to five minutes. It is wrong to make an assumption about someone’s condition because of how they were when you saw them</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Misconception</th>
<th>The condition is always the same</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reality</td>
<td>A neurological condition is a very individual condition, varying not only from person to person but within the same person over a matter of days, hours or even minutes</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Misconception</th>
<th>Neurological conditions do not cause pain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reality</td>
<td>Neurological conditions can cause pain, but sometimes people with these conditions are not able to express this due to problems with communication</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Misconception</th>
<th>People with neurological conditions need constant help</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reality</td>
<td>No they don’t, many people with neurological conditions live independently with little assistance for many years</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Misconception</th>
<th>Medication is the only useful therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reality</td>
<td>For many neurological conditions, medication is still the main therapy but speech and language therapy, physiotherapy and occupational therapy all have a very important role in the management of neurological conditions. Complementary therapies are also more widely used than before</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Misconception</th>
<th>Everyone can have their medicines at the same time and their treatment never needs to change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reality</td>
<td>Everyone’s needs and medicines are different - treat the individual. Each person’s neurological condition is individual. The condition changes over the years. As the condition changes, so the treatment needs to be assessed and possibly changed</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Misconception</th>
<th>‘Over the counter’ herbal medicines are always safe.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reality</td>
<td>It is important to remember that medicines that can be bought without a prescription are still drugs. These medicines may interfere with the condition or with the medicines prescribed for you by your doctors. This may also be true for herbal remedies. Always consult a doctor or pharmacist before taking these preparations.</td>
</tr>
</tbody>
</table>
Misconception  *Disabling neurological conditions do not always affect the intellect*

**Reality**
Depending on the condition, neurological conditions can be associated with intellectual problems. However, there is no direct correlation between physical disability and cognitive impairment: Some neurological problems such as motor neurone disease are rarely associated with intellectual impairment, whereas those with Huntington's Disease almost always suffer cognitive decline. Open discussion of this topic is required, and an assumption of intellectual integrity should be made with respect to all individuals with a neurological condition until there is clear evidence of cognitive decline. At all times, the dignity of the individual should be preserved.

Misconception  *When intellectual problems appear, they worsen rapidly*

**Reality**
This is dependent on the neurological condition.

Misconception  *Intellectual problems only occur in people who are significantly disabled*

**Reality**
On the contrary, people who are significantly disabled physically may have no cognitive problems at all.

Misconception  *Intellectual problems only occur late in the course of a disabling neurological condition*

**Reality**
There is little relationship between duration of the condition and the severity of cognitive dysfunction.
Access to Different Modes of Transport
In keeping with the Government’s commitment to improving accessibility of public transport for mobility impaired and disabled people, the following measures will be implemented:

- All new upgraded rail and bus stations financed under the Plan will be accessible to mobility impaired and disabled people;
- All light rail vehicles and suburban railcars under the Plan will be accessible to mobility impaired and disabled people;
- All buses purchased by CIE from 2000 for use on urban services will be low floor;
- A special provision of £10 million (13 million Euros) will be available to part-time accessibility improvements to existing public transport infrastructure and facilities;
- Each of the CIE operating companies will establish an Accessibility Unit and appoint a full-time Accessibility Officer to provide a focal point for accessibility issues to review all significant investment proposals from an accessibility perspective;
- The Minister for Public Enterprise will establish a Public Transport Accessibility Committee including representation from disability bodies; to advise on the accessibility aspects of proposed transport investment and other public transport issues.

### Recommendations on Access to Driving for Disabled Persons

**Introduction**

Mobility and access to public transport are critical components of function and independence, increasingly this means maintaining the ability to drive. Specialists involved with the care of acquired neurological disability (physical and/or mental) need to have some sense of background to mobility and driving needs of their patient population.

- Society places a clear preference on mobility over safety: otherwise the speed limit would be 20 mph and governors would be fitted to car engines to prevent any breach of speed limits.
- The elderly, the group most affected by acquired neurological conditions, are driving in greater numbers than ever before. Despite the higher prevalence of acquired neurological disability, this group has the safest accident record of any age group.
- There is a strong current of prejudice against both disability and age in our society, as reflected in barriers in driver-licensing policies, insurance premiums and the medical literature. Ireland has a process for medical screening of older drivers. This is despite preliminary evidence that this screening is harmful in public health terms: there is also no training in traffic medicine for practitioners. Insurance premiums may be unjustifiably high in the face of...
disability. The medical literature is also obsessed with determining who should not drive rather than on enabling those with disability to maximize their mobility options, including driving.

- Driving issues are often not explored with people suffering from neurological disability.
- In the current scheme in Ireland it is the nature and extent of the disability that determines a person’s entitlement rather than the condition which has given rise to it. Thus for example a person who is disabled as a result of an accident and a person who suffers a similar level of disability arising as a consequence of a medical illness or disease may both qualify on the basis of the same medical criteria.
- In this regard, currently less than 2% of the overall disabled community are in receipt of the disabled driver benefit. The current scheme was designed primarily to help people who, because of spinal cord injury, are rendered wholly or almost wholly wheelchair dependent and later was extended to include amputation of the lower limb. (Please see Appendix E: Summary of Regulations on Access to Driving for Disabled Drivers).
- Many disabled people with significant mobility problems due to other conditions (including those that are neurological in nature) do not qualify under the current scheme and get no help at all. In the future, it may be possible to agree to a point system based on an objective assessment of a person’s disability/mobility that is simple, easy to apply and scientifically validated.

**Recommendations on Process for Driving Evaluation**

- Driving and mobility needs should be considered for all people suffering from a neurological disability, and this should be followed by assessment in appropriate cases.
- The assessment should be aimed at maximizing mobility with a safety profile similar to that of the general population
- Specialist assessment and remediation should be available, including appropriate on-road testing, re-training and vehicle adaptation
- If driving is no longer possible, intensive efforts should be made to help the person maximize mobility: the absence of a para-transit system in Ireland is a major deficit in resolving this problem.

**Methodology**

A cascade methodology is appropriate:

A preliminary assessment may either reveal mild disease that does not require further evaluation at that time or uncover deficits which render driving illegal: i.e. hemianopia, advanced cognitive impairment or an epileptic seizure within the preceding year. In addition to a mental state and neurological examination, visual acuity and fields should be checked. Preliminary screening batteries for physical and mental fitness for use in primary care settings are being tested in Maryland.

A second level assessment with a comprehensive specialist multidisciplinary team that includes a Physician/Occupational Therapist/Physiotherapist/Neuropsychologist etc. may be helpful in deciding those who are clearly fit to drive and those whom it is inappropriate to assess on the road. Those who are considered ‘intermediate’ should be offered an on-road assessment. It is important to emphasize that not only should this assessment be holistic but it should also recognize that driving behaviour is an over-learned, hierarchical skill with many complex factors, including behaviour. Psychometric tests are poor correlates of driving skills and the overall assessment is clinical.

The third level is an on-the-road assessment/ driving instruction and includes advice on vehicle adaptation. This service is available both from the Disabled Drivers Association and the Irish Wheelchair Association.

As the majority of acquired neurological disabilities are progressive, a review date should be set for re-assessment.
The costs of these assessments should be regarded as an integral part of the healthcare costs of assessment and remediation of neurological disability. A centre gathering together a specialist with an interest in medical fitness to drive, associated team and access to specialist on-road assessment should be available in each Health Board area.

**Disclosure and Legal Issues**

- The process of mobility assessment should be openly discussed. Any advice and decisions should be recorded in writing in the patient’s notes.

- Those with neurological disability should be formally advised to review disclosure obligations as outlined in their insurance policy and also advised that non-compliance with these obligations may invalidate their insurance.

- The Department of the Environment guidelines on Medical Fitness to Drive is relatively non-prescriptive except for visual acuity, visual fields and epilepsy. This is appropriate in the light of the absence of a significant body of literature upon which to base more specific rulings. There is no specific obligation to inform the Department of the Environment (Ballina) and the absence of a Medical Section (as exists in the UK) lessens their role in licensing decisions.

**Continued Driving When No Longer Safe**

If the patient continues to drive in a manner likely to endanger others, despite maximum remediation, substitution where possible of mobility options and advice not to drive to both patient and family, patient-doctor confidentiality may be broken. The procedure has been mostly tested in the area of alcohol dependence, and only a District Court (not the Department of the Environment!) can remove a licence. As the patient may still continue to drive without a licence, a case-by-case process will need to be undertaken: referral to the Gardai, or immobilization of the vehicle by family/carers may be necessary.

**Support for Assisted Mobility**

The personal and societal cost of reduced mobility among those who have an acquired neurological disability is high, yet current support is restricted to a ludicrously narrow range of conditions. It is critical that mobility is recognized as a need and supported appropriately - the range of qualifying conditions should be expanded to include other forms of neurological disability, with function rather than disease entity as a cut-off point.

*The procedures/ Regulations outlined in Appendix E illustrate the present unacceptable situation.*

These recommendations were compiled by:

- Dr Des O’Neill, Consultant Physician in Geriatric Medicine, Tallaght Hospital (Adelaide and Meath inc. NCH)
- Dr Angela McNamara, Consultant in Rehabilitation Medicine and Chairperson of Disabled Drivers Medical Board of Appeal
- Dr Ray Murphy, Consultant Neurologist, Tallaght Hospital (Adelaide and Meath inc. NCH) and Member of Disabled Drivers Medical Board of Appeal
Section VIII

Predictive Testing in Inherited Neurological Conditions
Introduction
Adult onset inherited neurodegenerative disorders are most commonly passed from parent to child in an autosomal dominant manner, where an alteration in one of a person's two copies of a gene is sufficient to cause the disease. A person whose parent has an autosomal dominant condition has a 50% chance of inheriting the altered gene which has caused their parent's disease. This is in contrast to an autosomal recessive disorder, which requires both copies of a gene to be altered for a disease to develop. The majority of autosomal recessively inherited neurological conditions have their onset in childhood, and the health implications for the child of a person with an autosomal recessive condition are usually small.

Treatment
At present there is no cure for inherited neurodegenerative diseases. Many disease genes have been found such as those for Huntington's Disease (Huntingtin), two genes for early onset Alzheimer's, a gene for familial motor neurone disease (SOD1), two genes for rare forms of familial Parkinson's Disease (alpha synuclein and parkin), three for dystonia, two for Neurofibromatosis (NF1 and NF2) and nine for the Ataxias. Despite these advances, strategies to arrest or reverse the disease mechanisms remain elusive.

Recommendations
• Not everyone at risk wishes to know their status with regard to an inherited neurological condition, and it remains a highly individual choice to have a genetic test for an inherited neurological disorder. There is no right or wrong decision.
• All individuals have the right to decline genetic testing, or to choose to have genetic testing, when practicable.
• Genetic testing of a symptomatic individual for an exclusively inherited condition (e.g. an individual who has already developed features suggestive of Huntington's disease) should be undertaken with the consent of the person. In such cases, prior non-directive counselling may not be a pre-requisite to testing.
• Families should be made aware of the need for the availability of non-directive counselling.
• Genetic testing of an individual symptomatic for a condition, which is not exclusively genetic, should be undertaken only following counselling of the individual. An example would be SOD1 gene testing in Motor Neurone Disease, where the affects of SOD1 mutations are not easy to predict, and only a small number of people with Motor Neurone Disease have SOD1 gene alterations. Thus the implications for the relatives and offspring of an individual who has an altered SOD1 gene are unclear.
• Healthy asymptomatic adults with a family history of an inherited neurological condition who are interested in determining their genetic status should enter a recognised programme for predictive genetic testing. They should meet on several occasions with a geneticist, a trained genetic counsellor and a neurologist with expertise in the field to explore all the implications of the test results. This adults' only service should be available to all at risk adults. Waiting periods should be kept to a minimum. Testing of children should not take place until that child becomes a person who can fully and independently participate in the decision about a presymptomatic genetic test.
• The results of any such testing are strictly confidential to the person who has had the test. He or she may wish to communicate the result to the family. This confidentiality overrides the rights of insurance companies and employers to request the results of any genetic testing.
APPENDIX A

ABSTRACT FROM THE WORLD HEALTH ORGANISATION GUIDELINES ON COMMUNICATING BAD NEWS

WHO/MNH/PSF/93.2.B

Editor’s Note: For the purposes of this document, the words Multiple Sclerosis have been substituted for the word Cancer and as such the text has been revised slightly. This has been done without the permission of the W.H.O.

When the News is Bad, What Information should be Disclosed and How Should it be Done?

The individualised disclosure model is recommended. This means that the amount and rate of disclosures will be determined by negotiation based on a relationship of mutual trust and confidence between doctor and patient.

The key questions to be addressed by the doctor are "How much information does this patient want?" and "How should I break the news?"

How much Information does the Patient Want?

The way to discover this is to ask the patient, and to do so in an atmosphere which encourages an honest answer (i.e. within the context of a non-threatening partnership relationship).

When the patient first presents to the General Practitioner or specialist, it is wise to raise the question of a serious diagnosis. A patient with dragging of a leg and a background history of visual disturbance may have thought of MS but it is of course sensible to acknowledge this as a possibility at the outset, while at the same time giving a perspective on other possible causes.

At this stage, the doctor can begin dialogue with the patient about his/her life situation and the meaning that a diagnosis of MS would have for the family unit. At the same time an MS education programme aimed at dealing with any frightening misconceptions about MS which the patient may have can be introduced in a low key way.

At some point, the patient should be asked how much information he/she would want to be given in the event of the diagnosis being MS. Honest sharing and evaluation of probabilities in these ways can initiate a relationship of mutual confidence and trust. This will provide a foundation on which to build later.

At the time of positive diagnosis, the patient should again be asked what he/she wishes to be told and his/her wishes in the matter should be respected. For example, there may be a desire to hear the diagnosis but nothing more – at least at that time. Where a patient chooses not to be informed or delegates to another the responsibility of treatment decision-making, the legal position with regard to the requirement of informed consent needs to be considered.

Informed consent is that which is obtained after a patient has been given sufficient explanation about a treatment or procedure to understand its possible risks and benefits. If a patient does not wish to be informed and makes this quite clear, a doctor need not force information upon him. A doctor may also modify the extent of the disclosure to avoid causing the patient "unnecessary anxiety, apprehension or distress".
Who should break the bad news and what is the doctor’s role?

The doctor should be:

**Available**
- as a source of honest and clear information to the patient
- as a person prepared to give whatever time is necessary to inform the patient to whatever extent he/she wants to be informed
- as a source of continuing support and encouragement as long as is needed, letting it be known that grief, anger and despair are normal and can be safely expressed in his/her presence
- as a person who will listen, encourage questions and instill legitimate hope that a full valuable life can still be lived
- as a person prepared to spend time exploring alternatives with the patient in an atmosphere of security and mutual trust
- as a person prepared to see the patient through, even when cure is not likely

**Vulnerable**
- prepared to receive the patient’s anger, pain and grief, which may be echoed in his/her own life
- prepared to have his/her professional competence challenged
- prepared not to have all the answers

Parkes (1974) summed up the role of the physician as to “help people to live until they die by creating a situation in which fear of dying doesn’t spoil joy at living”.

When should it be done?

As soon as the diagnosis is certain, the news should be given to the patient. Waiting at this stage can be very distressing.

Where should it be done?

In a place that is quiet and private. It should not be done at the patient’s bedside in the presence of other patients.

Who should be present?

The patient has the fundamental right to control access to information about him/herself and therefore should be told first. Whether or not the partner and/or others are present is for the patient to choose. If the partner is not present, it is highly desirable that he/she be informed and involved as soon as possible. The purpose of this is partly so that patient and partner can support one another from the time of diagnosis onwards. The other advantage is that the partner may well recall or understand information which the patient missed.
How should the patient be told?

Aim

• to break the initial news gently, honestly and with sensitivity

• to avoid technical jargon or euphemisms which would obscure the truth

• to give as much further information as the patient wants

• to implant genuine hope

• to convey to the patient that you have plenty of time for discussion and/or simply to be available

Method

This depends on the patient. Some will immediately ask their diagnosis. Others will come around to the question more slowly. Others will need to be drawn out. A useful way of doing this is to go over the sequence of events which have preceded this interview and then ask the patient what he/she would like to know. The more the possibility of a specific condition and its implication for the patient have been discussed earlier, the more readily the issue can be faced. While there is no way of escaping the realities of the information, *yes, I’m afraid it is*, to convey at the same time that you really care and will help.

Allow the patient to express his/her feelings freely, making it clear that it is all right to do so. Don’t try to stop the flow of emotion or to provide pat answers. Where appropriate, an arm around the shoulder or a hand on an arm will speak much more effectively.

Give as much or as little further information as the patient asks for. Don’t try to give a precise prognosis. They are almost always wrong and this can be very distressing. Speak honestly in terms of the range of possibilities.

Begin to instill hope as soon as possible (i.e. that a full and valuable remaining life is possible and that you will do all you can for as long as you are needed to help make this possible).

Do not allow the patient to go without making arrangements to see him/her again soon and without giving him/her your telephone number and permission to contact you at any time with questions.

What further can be done?

It is important for the patient’s emotional well-being that this be seen as the beginning of a partnership characterised by continuing dialogue, mutual confidence, trust and respect. Begin as early as possible to encourage the patient to talk about the meaning of the illness for the whole of his/her life and that of the family. Remember that the quality of the patient’s life has physical, emotional, social and spiritual dimensions. All of these need to be patiently worked through as part of the disclosure process.

Referral to others able to help in particular areas may be needed but the primary physician will remain the ‘anchor person’. All this takes time and it takes work. However, the physician who perseveres in such a partnership will find him/herself in a very privileged position, being not only able to offer support to a person in great need but also to learn a great deal.
**APPENDIX B**

**NEUROLOGY IN THE REPUBLIC OF IRELAND:**

**ADDRESSING THE UNMET NEEDS OF PEOPLE WITH NEUROLOGICAL DISORDERS IN IRELAND**

**IRISH CONSULTANT NEUROLOGISTS ASSOCIATION.**

**JUNE 1999**

**Summary**

1. The number of neurologists in the Republic of Ireland needs to increase in order to provide adequate services for those patients with neurological disorders.

2. Based on data derived from the United Kingdom it is estimated that to serve the needs of patients in Ireland a minimum number of one whole time neurologist per 100,000 population is required. This would indicate a minimum need for 35 neurologists.

3. Given the present complement of 11 consultant neurologists it is recommended that there should be a planned steady increase of neurologists each year until this deficit is corrected.

4. Neurologists will have an attachment to neurosciences or a neurology centre and will also work in a general hospital. Most work of consultant neurologists is performed outside neuroscience centres but an attachment is necessary to ensure continuing excellence in medical care in the face of increasing complexity of diagnosis and treatment of neurological disorders.

5. The number of consultant neurophysiologists needed will be ten (one for each of the teaching hospitals in Dublin; St. Vincent’s Hospital, Tallaght Hospital, St James’ Hospital, the Mater Hospital, one for the University College Hospital Galway, two for the neuroscience centre in Cork University Hospital and three in Beaumont Hospital).
APPENDIX C

REHABILITATION MEDICINE IN THE REPUBLIC OF IRELAND:

ADDRESSING THE UNMET NEEDS OF PEOPLE WHO NEED ACCESS TO REHABILITATION MEDICINE SERVICES

IRISH CONSULTANTS IN REHABILITATION MEDICINE

FEBRUARY 2000

Summary

1. The number of Rehabilitation Specialists in the Republic of Ireland needs to increase in order to provide adequate services for those patients who need rehabilitation medicine services.

2. Based on data derived from the United Kingdom it is estimated that to serve the needs of patients in Ireland, a minimum number of one whole time Rehabilitation Medicine Specialist per 250,000 population is required. This would indicate a minimum need for 15 Rehabilitation Medicine Specialists. There is currently no specialist service for the private sector.

3. Given the present complement of 3 Rehabilitation Medicine Specialists it is recommended that there should be a planned steady increase of Rehabilitation Medicine Specialists each year until this shortfall is corrected.

4. Rehabilitation Medicine Specialists should normally have an attachment to a Neurosciences Centre as well as a General Hospital to facilitate research.

5. It is recommended that Specialists do not work in isolation (i.e. that there should be a minimum of 2 Specialists per Rehabilitation Centre to facilitate specialisation, continuity of care and the capacity to train new Specialists).

6. Early Rehabilitation facility requires input from a wide-ranging multidisciplinary team.
APPENDIX D

GERIATRIC MEDICINE IN THE REPUBLIC OF IRELAND

ADDRESSING THE UNMET NEEDS OF PEOPLE WITH NEUROLOGICAL DISORDERS IN IRELAND

IRISH SOCIETY OF PHYSICIANS IN GERIATRIC MEDICINE

MARCH 2000

Summary

1. The number of Geriatricians in the Republic of Ireland needs to increase in order to provide adequate services for those patients with neurological disorders in older age. This is particularly so as geriatricians have pioneered the development in Ireland of specialised services for stroke and dementia and are actively involved in the diagnosis and management of Parkinson’s Disease.

2. Based on data derived from the United Kingdom it is estimated that to serve the needs of patients in Ireland a minimum number of one whole time Geriatrician per 10,000 population over 65 years of age is required. In terms of the population aged 75 years and over it is recommended that there be one Geriatrician per 4,000 of the population.

3. Given the present complement of 32 Consultant Geriatricians it is recommended that there should be a planned steady increase of Geriatricians each year until this deficit is corrected.
APPENDIX E

SUMMARY OF REGULATIONS ON ACCESS TO DRIVING FOR DISABLED DRIVERS AND PASSENGERS AND OTHER ISSUES IN RELATION TO DRIVING

DISABLED DRIVERS

Procedure for claiming Vehicle Registration Tax (V.R.T.) and V.A.T. by Disabled Drivers

People with a progressive and disabling neurological condition should qualify for a tax exemption for car modifications as long as their neurologist or geriatrician (or other specialist where appropriate) is prepared to state in writing to the relevant authorities that they are safe to drive.

First Time Buyers

Medical Certification

In the case of first time buyers only, the person must obtain a Primary Medical Certificate from the Director of Community Care in his/her local Health Board.

If they satisfy medical criteria, the vehicle must be adapted to suit the person’s disability.

The medical criteria are as follows:

- The applicant is wholly or almost wholly without the use of both legs
- The applicant is wholly without the use of one leg and almost wholly without the use of the other leg such that the applicant is severely restricted as to the movement of the lower limbs
- The applicant is without both hands or without both arms
- The applicant is without one or both legs
- The applicant is wholly or almost wholly without the use of both hands or arms and wholly or almost wholly without the use of one leg
- The applicant has the medical condition of dwarfism and has serious difficulties of movement of the lower limbs.

Vehicle Refunds

The person can now apply for refunds for their car in one of two ways:

A. Remission of V.R.T at Registration and repayment later of V.A.T (Application to Central Vehicle Office)
B. Repayment of V.R.T. and V.A.T.

Second Hand Vehicles

Refunds can now be claimed on second hand vehicles purchased from garages registered for V.A.T. and also on vehicles purchased by a person before becoming disabled (on or after 1/12/94).

The total amount (both VRT and VAT) which may be remitted and/or re-paid shall not exceed £7,500 in respect of any one specially constructed or adapted vehicle. The remission and/or repayment is subject to the qualifying person using the vehicle in question for 24 months from its date of purchase or the date of lodging the claim.
The vehicle must be purchased by and registered in the name of the disabled driver

A vehicle acquired under any other form of lease arrangement does not qualify

A vehicle with an engine size of 2,000 c.c. does not qualify

All forms are available at:
The Disabled Drivers Association of Ireland offices;

Disabled Drivers Association
Ballindine, Co. Mayo
Tel: (094) 64054/64266

Or from
Ms Sheila O’Donoghue, Secretary
Disabled Drivers Association
6 South Terrace, Cork
Tel: (021) 313033

Completed Application Form for Remission of V.R.T. and Repayment of V.A.T. to be forwarded to
The Central Repayments Officer (CRO)
Coolshannagh
Monaghan

DISABLED PASSENGERS
Procedure for claiming Vehicle Registration Tax (V.R.T.) and V.A.T. by Disabled Passengers

First Time Buyers

Medical Certification

In the case of a first time buyer, you must obtain a Primary Medical Certificate (from the Director of Community Care in your local Health Board) first time buyers only. In addition to satisfying the medical criteria the vehicle must be adapted to take account of the person’s disability. This adaptation has a minimum percentage cost requirement of 10% of the basic price of the vehicle.

Vehicle Refunds

You can now apply for refunds for your car in one of two ways

A. Remission of V.R.T. at Registration and repayment later of V.A.T. (Application to Central Vehicle Office)
B. Repayment of V.R.T. and V.A.T. (Application to Central Vehicle Office after purchase of your car)

Second Hand Vehicles

Refunds can now be claimed on second hand vehicles purchased from garages registered for V.A.T. and also on vehicles purchased by a person before becoming disabled (on or after 1st of December 1994).
The total amount (both V.R.T. and V.A.T.) which may be remitted and/or re-paid shall not exceed £12,500 in respect of any one specially constructed or adapted vehicle. The remission and/or repayment is subject to the qualifying person using the vehicle in question for 24 months from its date of purchase or the date of lodging the claim.

- The vehicle must be purchased by the disabled passenger or by a family member residing with and responsible for the transportation of that disabled person
- A vehicle acquired under any other form of lease arrangement does not qualify
- A vehicle with an engine size of 4,000 c.c. does not qualify

All forms are available at:
The Disabled Drivers Association of Ireland offices;

Disabled Drivers Association
Ballindine, Co. Mayo
Tel: (094) 64054/64266

Or from
Ms Sheila O’Donoghue, Secretary
Disabled Drivers Association
6 South Terrace, Cork
Tel: (021) 313033

Completed Application Form for Remission of V.R.T. and Repayment of V.A.T. to be forwarded to
The Central Repayments Officer (CRO)
Coolshannagh
Monaghan

If a disabled person has been refused a Primary Medical Certificate by the Director of Community Care, he/she has a right to appeal to the Disabled Drivers Medical Appeals Board, c/o National Rehabilitation Board, 25, Clyde Road, Ballsbridge, Dublin 4 Tel.: 6684 181 (Please note that this address may be changing shortly)
ADAPTATION FIRMS IN IRELAND

The following is a list of firms and garages who supply, manufacture and/or fit adaptive driving controls for disabled drivers.

All entries are correct at the time of writing. Some firms may not be mentioned here but this is only because we are not aware of their business or expertise in this area.

ARMAGH
McElmeens Greg Limited
Ballyscandal Road
Armagh
Co. Armagh
Tel: (0801) 861525333

Manufacturers of hand controls and agents for all Calvern equipment. Also Northern Ireland Agent for Steering Developments Ltd; UK power steering adjustment firm.

CLARE
Lemtronics Limited
Ballycar
Newmarket-on-Fergus
Co. Clare
(Sean Leemy)
Tel.: (061) 368385

Distribution and fitting agents for all Calvern equipment. Irish manufacturers of Hand Control, Steering Spinners, Left side accelerator pedals etc.

CORK
Calven Mobility Clutches Limited
Ballincrokig
White Cross
Cork
(Michael O‘Callaghan)
Tel.: (021) 393521

Main agents for Guidosimplex Italy, Manufacturers of the electronic clutch system and steering ring. Agents for Autichair, rooftop wheelchair stowage unit. Agents for Carmobility, England, manufacturers of swivel seat system for driver and passenger.

DERRY
Haslett Garages Limited
Claudy
Co. Derry
Northern Ireland
Tel.: (0801) 504 338329

DUBLIN
Coyles Garage Limited
21 The Crescent
Monkstown
Co. Dublin
Tel.: (01) 284 3875/ 284 1196

DUBLIN
D.A.D. Limited
53 Rathlawns
Rathcoole
Co. Dublin
(Dave Daly)
Tel.: (01) 458 9783

Distribution and fitting agent for all Calvern equipment

DUBLIN
McMeels
South Gloucester Street
Dublin 2
(Paddy McMeel)
Tel.: (01) 677 1110

Fitters of swivel seats and AID & Vekker Hand Controls. Also agents for most adaptive driving equipment

KILLARNEY
O.C. Mobility
Currow
Killarney
Co. Kerry
Tel.: (066) 64738

Distribution and fitting agent for all Calvern equipment

KILKENNY
Cuddihy Mobility Limited
Lyle
Kilmanaagh
Co. Kilkenny
Tel.: (056) 69121
(John Cuddihy)

Distribution and fitting agent for all Calvern equipment
**LAOIS**
Midland Mobility Ltd
Ballyfin
Portlaoise
Co. Loaise
Tel.: (0502) 55200

**LOUTH**
Mobility Motors Ltd
Donaghmore
Carrick Road
Dundalk
Co. Louth
(Matt O'Brien)
Tel.: (042) 9336240

(Distribution and fitting agent for all Calvern equipment)

**ROSCOMMON**
Boyle Technology
Clonloo
Boyle
Co Roscommon
Tel.: (079) 62160

**WESTMEATH**
Clonfad Mobility Conversions
Clonfad
Kinnegad
Co. Westmeath
(David Lynch)
Tel.: (044) 74678

**WEXFORD**
Eastern Mobility
Ballinclay
Killurin
Co. Wexford
(Billy Donohoe)
Tel.: (053) 28287

**LEITRIM**
Vesey Mobility
Tuilly
Dromahair
Co. Leitrim
(Seamus Vesey)
Tel.: (071) 64515
MOTOR INSURANCE

Many people with a disability who want to begin driving, or return to driving, have great difficulty in securing suitable and affordable car insurance.

It would appear that many insurance companies are reluctant to insure someone with a disability, thinking that they are a greater risk as a driver. Whilst there is no statistical evidence to support this line, insurance companies often err on the side of caution and may be less likely to give a keen quotation at first.

Experience in Ireland, backed by experience of other countries, indicates that disabled drivers are usually more careful drivers and have fewer accidents than their able-bodied peers. One possible reason for this is that people with disabilities rely more heavily on their cars as their only means of outdoor mobility.

If you had insurance before you became disabled, it is advisable to return to your previous insurance company and ask them for a quote in the first instance.

There are a few companies who offer insurance without any loading. One source of this facility is through an insurance broker. Often brokers can place insurance business with a variety of companies and ‘shop around’ to get the best price.

Two such insurance brokers offer a service to disabled motorists in Ireland.

They can be contacted at:
Rooney Gallagher Insurances
Disabled Persons Insurance Scheme
396 North Circular Road
Phibsboro, Dublin 7
Tel.: (01) 830 3599

Richardson’s Insurance Brokers
1, Priory Lawn
Stillorgan
Co. Dublin
Tel.: (01) 283 4155
APPENDIX F
DISCRIMINATION IN EMPLOYMENT

The Disability Discrimination Act (DDA) 1995
The Disability Discrimination Act seeks to end discrimination against people with disabilities. Employers that enter into both the spirit and letter of this act will benefit from a wider pool of talent and experience. All people must be valued as individuals and it is therefore crucial to concentrate on personal abilities and strengths in order to ensure organisations gain from diversity. Having a disability does not automatically stop an individual from being the best person for the job. It therefore makes sound economic and employment sense for employers and service providers to capture the contributions of people with disabilities both as employees and customers. Evidence shows that there are not necessarily additional costs involved in taking action to do this. There are in fact advantages in terms of tapping skills and talent and the potential for growth in markets and improved customer satisfaction.

The Disability Discrimination Act (DDA) gives rights in
- Employment
- Access to goods and services
- Buying or renting land or property
(These are enforceable from different dates)

Under the Act it is unlawful
- To discriminate against a disabled person in employment
- For an employer to fail to provide any necessary reasonable adjustments for disabled employees and applicants
- To provide lower standards or refuse service and offer less favourable terms to disabled people
- To discriminate when selling or letting land and property

Other provisions covering policies and procedures, additional help and services, removing physical impediments and trade organisation responsibilities are also effective from different dates.

Structurally the Act defined disability as ‘a physical or mental impairment which has a substantial or long-term adverse effect on a person’s ability to carry out normal day-to-day’ activities.

Effects on employers
The Act makes it unlawful for employers with fifteen or more staff to discriminate against current or prospective employees with disabilities because of reasons relating to disability.

Employers have to make reasonable adjustments to make sure people defined, as disabled in law are not disadvantaged. They must show that practical steps have been considered for discrimination to be justified. Guidance on reasonable adjustments and justifiable discrimination is given in the Code of Practice.
**Unlawful Discrimination**

Discrimination occurs when a disabled person is treated less favourably than a person without a disability and

- The treatment is given for a reason relating to the person’s disability and the reason does not apply to the other person
- This treatment cannot be justified

**Avoiding Employment Discrimination**

In employment, organisations must not discriminate against a disabled person in connection with

- Recruitment and retention
- Promotions and transfers
- Training and development

**The Employment Equality Act, 1998**

The Employment Equality Act outlaws discriminatory practices in relation to and within employment. The Act prohibits direct and indirect discrimination and victimisation in employment on nine grounds

- Gender
- Marital Status
- Family Status
- Sexual Orientation
- Religion
- Age
- Disability
- Race
- Membership of the Traveller Community

**All aspects of employment are covered**

- Equal pay
- Access to employment
- Vocational training
- Conditions of employment
- Work experience
- Promotion
- Dismissal
The legislation applies to

- Public and private sector employment
- Employment agencies
- Vocational training bodies
- The publication of advertisements
- Trade Union and professional bodies
- Full-time and part-time workers
- Collective agreements

Discrimination is defined as less favourable treatment. A person is said to be discriminated against if he is treated less favourably than another is, has been or would be treated on any of the nine grounds. To establish discrimination, a direct comparison must be made.

The Act defines disability to include total or partial absence of bodily or mental faculties, chronic disease, whether manifest or not, learning and personality disorder. It includes a condition, illness or disease which affects a person’s thought processes, perception of reality, emotions or judgement or which results in disturbed behaviour and shall be taken to include a disability which exists at present, or which previously existed but no longer exists or which may exist in the future or which is imputed to a person.
APPENDIX G

THE IRISH NEUROLOGICAL ALLIANCE

The Irish Neurological Alliance is an umbrella organisation representing the collective goals of many individual neurological charities. By uniting the efforts of many into one voice, the Alliance aims to secure improved care and public support for people with a neurological condition; to inform and influence policy makers on the unique needs of these people; and to act as a channel for mutual collaboration on models of care, technology, research and education. The Alliance is committed to pursuing the highest standard of service and care for all people affected by a neurological condition, their families and caregivers. Membership is open to any organisation that represents patients with a neurological condition.

For further information, please contact the
Irish Neurological Alliance
PO Box 6113, Dublin 9
Tel.: (01) 837 9087, Fax.: (01) 837 6982

The Irish Neurological Alliance members for which these Standards of Care for People with Disabling Neurological Conditions (Progressive and Static) are relevant are as follows;

<table>
<thead>
<tr>
<th>Alzheimer Society of Ireland</th>
<th>Dystonia Ireland</th>
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<tbody>
<tr>
<td>Alzheimer House</td>
<td>Harold’s Cross, Dublin 6W</td>
</tr>
<tr>
<td>43 Northumberland Avenue</td>
<td>Tel.: (01) 492 2514</td>
</tr>
<tr>
<td>Dun Laoghaire, Co. Dublin</td>
<td>Fax.: (1) 492 2265</td>
</tr>
<tr>
<td>Tel.: (01) 284 6616</td>
<td>Friedreich’s Ataxia Society of Ireland</td>
</tr>
<tr>
<td>Fax.: (01) 284 6030</td>
<td>San Martino</td>
</tr>
<tr>
<td>E-mail: <a href="mailto:alzheim@iol.ie">alzheim@iol.ie</a></td>
<td>11 Mart Lane</td>
</tr>
<tr>
<td>Website: <a href="http://www.alzheimer.ie">www.alzheimer.ie</a></td>
<td>Foxxrock</td>
</tr>
<tr>
<td></td>
<td>Dublin 18</td>
</tr>
<tr>
<td></td>
<td>Tel.: (01) 289 4788</td>
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<tr>
<td></td>
<td>Fax: (01) 289 4788</td>
</tr>
<tr>
<td></td>
<td>E-mail: <a href="mailto:fasi@tinet.ie">fasi@tinet.ie</a></td>
</tr>
<tr>
<td></td>
<td>Web site: homepage.tinet.ie/~fasi</td>
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<thead>
<tr>
<th>Brainwave – Irish Epilepsy Association</th>
<th>Headway Ireland</th>
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<tbody>
<tr>
<td>249 Crumlin Road, Dublin 7</td>
<td>101 Parnell Street</td>
</tr>
<tr>
<td>Tel.: (01) 455 7500</td>
<td>Dublin 1</td>
</tr>
<tr>
<td>Fax.: (01) 455 7013</td>
<td>Tel.: (01) 872 9222</td>
</tr>
<tr>
<td>E-mail: <a href="mailto:brainwave@iol.ie">brainwave@iol.ie</a></td>
<td>Fax.: (01) 872 9590</td>
</tr>
<tr>
<td></td>
<td>E-mail: <a href="mailto:headwaves@aonad.iol.ie">headwaves@aonad.iol.ie</a></td>
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<tr>
<th>Cerebral Palsy Ireland</th>
<th>Huntington’s Disease Association</th>
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<tr>
<td>Sandymount</td>
<td>Carmichael House</td>
</tr>
<tr>
<td>Dublin 4</td>
<td>North Brunswick Street, Dublin 7</td>
</tr>
<tr>
<td>Tel.: (01) 269 5355</td>
<td>Tel.: (01) 872 1303</td>
</tr>
<tr>
<td>Fax.: (01) 269 4983</td>
<td>Fax.: (01) 872 9931</td>
</tr>
<tr>
<td>E-mail: <a href="mailto:michele.white@oceanfree.net">michele.white@oceanfree.net</a></td>
<td>FreeFone: 1800 393939</td>
</tr>
<tr>
<td>Website: <a href="http://www.cpireland.ie">www.cpireland.ie</a></td>
<td>Minicall: 08 224 24837</td>
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<tr>
<td></td>
<td>E-mail: <a href="mailto:hdai@indigo.ie">hdai@indigo.ie</a></td>
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<tr>
<th>Dyspraxia Association</th>
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<tr>
<td>Capri</td>
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<tr>
<td>5 Blackglen Court</td>
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<td>Sandyford</td>
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<tr>
<td>Dublin 18</td>
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<tr>
<td>Tel.: (01) 295 7125</td>
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<tr>
<td>E-mail: <a href="mailto:dyspraxi@indigo.ie">dyspraxi@indigo.ie</a></td>
<td></td>
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<tr>
<td>Web site: <a href="http://indigo.ie/~dyspraxi/">http://indigo.ie/~dyspraxi/</a></td>
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</table>
Irish Association for Spina Bifida and Hydrocephalus
Old Nangor Road
Clondalkin
Dublin 22
Tel.: (01) 457 2326
Fax.: (01) 457 2328
E-mail:iasbah@indigo.ie

Irish Brain Research Foundation
PO Box 6113
Dublin 9
Tel.: (01) 837 9089
Fax.: (01) 837 6982
E-mail: ibrf@indigo.ie

Irish Motor Neurone Disease Association
Carmichael House
North Brunswick Street
Dublin 7
Tel.: (01) 873 0422
Fax.: (01) 873 5737
Freephone: 1800 403403

Myasthenia Gravis Association
20 Galbraith Gardens
Waringstown
BT66 7QN
Tel.: 01762 820058
E-mail: mga@jennipower.freeserve.co.uk

Multiple Sclerosis Society of Ireland
Royal Hospital Donnybrook
Dublin 4
Tel.: (01) 269 4599
Fax.: (01) 269 3746
Confidential phone line: 1850 233 233
e-mail: mssoi@iol.ie
Website: www.ms-society.ie

Muscular Dystrophy Ireland
Carmichael House
North Brunswick Street
Dublin 7
Tel.: (01) 872 1510
Fax.: (01) 872 4482
Freephone: 1800 245300
E-mail: info@mdi.ie

Neurofibromatosis Association of Ireland
Carmichael House
North Brunswick Street, Dublin 7
Tel: (01) 872 6338
Fax: (01) 873 5737

Parkinson’s Association of Ireland
Carmichael House
North Brunswick Street
Dublin 7
Tel.: (01) 872 2234
Fax.: (01) 873 5737
Freephone: 1800 359359

Post Polio Support Group
Carmichael Centre
North Brunswick Street
Dublin 7
Tel.: (01) 873 0338
E-mail: ppsg@eircom.net

For those members of the Irish Neurological Alliance who need access to/ advice on wheelchair use, please contact

Irish Wheelchair Association
Aras Cuchulainn,
Blackheath Drive,
Clontarf, Dublin 3, Ireland.
Tel: (01) 833 8241
Fax: (01) 833 3873
e-mail: info@iwa.ie
website www.iwa.ie

(Please note that the Irish Wheelchair Association is not a member of the Irish Neurological Alliance)

The Irish Wheelchair Association is the national organisation dedicated to the achievement of full social, economic and educational integration of people with disabilities as equal, independent and participative members within the general community. The IWA aspires to be the leading organisation in Ireland of and for people with physical disability; giving voice to the demands of all members and taking action at local, national and international levels in order to achieve these objectives. Leaflets are available for every service which the Irish Wheelchair Association provides.
APPENDIX H
THE CARERS ASSOCIATION

The Carers Association Ltd. is the national voluntary organisation representing the interests of Carers in the home. The Association is owned and controlled by Carers and is totally dedicated to the needs of Carers. It has 70 branches and affiliated groups throughout the country. The Association provides an extensive range of support including:

- It operates Carers’ Resource Centres which are dedicated to improving the quality of life for Carers and the person being cared for by providing HomeCare Assistants (100 employed nationally).
- It deals with enquiries on a variety of welfare, social care, health care, personal, awareness and advocacy issues.
- It operates Carers Outreach and Empowerment Programmes which emphasise the need for self-development, leadership and empowerment of Carers in the community.
- It operates a Carer-to-Carer programme linking former and current Carers.
- It operates Young Carers Liaison Service which helps to identify and address the particular needs of Young Carers.
- It provides information on Tax Relief.
- It provides a freefone National CareLine for Carers in the home, a vital link for the isolated Carer.

For further information, please contact:

The Carers Association
St Mary’s Community Centre
Richmond Hill
Rathmines
Dublin 6.
Tel: (01) 497 4498/497 4131.
Fax: (01) 497 6108.
Freefone 1800 24 07 24.
E-mail: takecare@carersireland.com
Website: www.carersireland.com
APPENDIX I
RECOMMENDED READINGS

Alzheimer’s Disease
- Alzheimer’s Disease – Prevention, Intervention and Treatment
  Elwood Cohen, M.D., Keats Publishing
- Alzheimer’s at Your Fingertips
  Harry Cayton, Dr Nori Graham & Dr James Warner, Class Publishing London
- Dementia Reconsidered - The Person Comes First
  Tom Kitwood, Oxford University Press, 1999
- Person to Person – A Guide to the Care of those with Failing Mental Powers
  Tom Kitwood, and Kathleen Bredin, Gale Centre Publications, 1992

Cerebral Palsy
- Handling a Child with Cerebral Palsy
  Nancy Finney
- Children with Cerebral Palsy – A Parent’s Guide
  Edited by Elaine Geralis (Woodbine House 1998)
- Coping with Cerebral Palsy –Answers to Questions Parents often Ask
  J. Schleickorn 2nd Edition

Dyspraxia
- Information Pack
  Available from Dyspraxia Association
  (contains Practical Hints that may help in the classroom, behavioural indicators of Developmental Dyspraxia, Information Sheets on Developmental Verbal Apraxia and Performing Tasks while Seated. Other issues also covered)

Dystonia
- Q&A about Dystonia – Causes, Effects, Genetics and Treatments
  Published by Affiliated National Dystonia Associations 1999
- Thank you for Asking - A Response -Resource Coping Book
  Valerie F. Levitan, Pd.D Published by the Dystonia Medical Research Foundation, 1998
- Speechless: Living with Spasmodic Dysphonia.
  Published by the National Dysphonia Association in collaboration with Dot Sowerby, Jean Newcomer and Bety Schonauer, 1999

Epilepsy
- Epilepsy A Parent’s Guide
  Prof. Joe Mc Menamin and Ms. Mary O’Connor Bird (published by Brainwave)
- A Diagnosis of Epilepsy
  Gillian Hart and Peter Rogan (published by Brainwave)
- Living with Epilepsy
  Sue Usiskin and Prof. David Chadwick (published by McDonald Optima available from Brainwave)
- Epilepsy at your fingertips
  Brian Chappell & Dr.Pamela Crawford (published by Class Publishing)

Friedreich’s Ataxia
- Useful Information for Lay People
  Produced by Frederick’s Ataxia Society of Ireland, February 1993

Head Injury
- Head Injury Management
  Dr Martina O’Connor
- Head Injury – A Practical Guide
  Trevor Power
- Living with Head Injury
  MD Van Dan Brook, W Schendy and MJ Coyne
<table>
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<tr>
<th>Condition</th>
<th>Title</th>
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<tr>
<td>Huntington’s Disease</td>
<td>Huntington’s Disease – The Facts</td>
<td>Oliver Quarrell, Sheffield Children’s Hospital</td>
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<td>Motor Neurone Disease</td>
<td>Motor Neurone Disease – What is It?</td>
<td>Published by Health Promotion Unit, Department of Health and Children, Updated 1998</td>
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<td>Living with Motor Neurone Disease</td>
<td>Published by MND Association, August 1996</td>
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<td>Multiple Sclerosis</td>
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<td></td>
<td>Sexuality and Multiple Sclerosis</td>
<td>Mary Leonard/ Multiple Sclerosis Society of Ireland</td>
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<td></td>
<td>Taking Control of your Emotions</td>
<td>Multiple Sclerosis Society of Ireland</td>
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<td></td>
<td>Coping with Multiple Sclerosis</td>
<td>Cynthia Benz/ Optima Books</td>
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<td></td>
<td>Self Help for MS</td>
<td>Judy Graham/ Faber</td>
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<td></td>
<td>What everybody should know about MS</td>
<td>Multiple Sclerosis Society of Ireland</td>
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<td></td>
<td>Multiple Sclerosis: Guide for newly diagnosed</td>
<td>Nancy Holland/ T. Jock Murray/ Stephen Rheingold</td>
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<td>Focus for MS</td>
<td>Michael Shemeld, Southern Health Board, Regional Survey</td>
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<td>Multiples Challenges</td>
<td>Aidan Larkin, Western Health Board Regional MS Report.</td>
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<td>Myasthenia Gravis</td>
<td>Myasthenia Gravis – An Introduction</td>
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<td></td>
<td>Give us Strength to Fight Myasthenia Gravis</td>
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<td>A Practical Guide to Myasthenia Gravis</td>
<td>All produced by Myasthenia Gravis Association</td>
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<td>A Practical Guide to Ocular Myasthenia</td>
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<tr>
<td>Neurofibromatosis</td>
<td>Neurofibromatosis - Handbook for patients, families &amp; healthcare professionals</td>
<td>Rubenstein &amp; Korf</td>
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<tr>
<td></td>
<td>Understanding Neurofibromatosis</td>
<td>Sue Hewson, Consultant Geneticist, Oxford Radcliffe Hospital, England.</td>
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<tr>
<td></td>
<td>LD does not mean learning dumb</td>
<td>Neurofibromatosis Association of Ireland</td>
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<td>Introduction booklet to Neurofibromatosis.</td>
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<td><strong>Parkinson’s Disease</strong></td>
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<tr>
<td>Parkinson’s at Your Finger Tips</td>
<td>Marie Oxtoby and Adrian Williams</td>
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<td>Parkinson’s – A Patient’s View</td>
<td>Sidney Dorros</td>
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<td>Parkinson’s Disease – Doctors and Patients</td>
<td>John Williams</td>
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<tr>
<th><strong>Post Polio</strong></th>
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<tr>
<td>The Late Effects of Polio,</td>
<td>Post Polio Support Group Information Leaflet</td>
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<tr>
<td>Information for Healthcare Providers by</td>
<td>Charlotte Leboeuf</td>
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<tr>
<td>A Practical Approach to the Late Effects of Polio</td>
<td>Charlotte Leboeuf</td>
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<td>Understanding Nonverbal Learning Disability</td>
<td>Wendy Heller</td>
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<td>Learning among children with Spina Bifida</td>
<td>Donald J Lollar</td>
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<tr>
<td>Stress, Anxiety, Panic and Phobia Secondary to NLD</td>
<td>Sue Thompson</td>
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<tr>
<th><strong>Spinal Injuries</strong></th>
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<tr>
<td>Moving Forward</td>
<td>Available from Spinal Injuries Association, UK</td>
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<tr>
<td>Information Pack</td>
<td>Tel.: 0044-181-4442121</td>
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<th><strong>Stroke</strong></th>
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<td>After Stroke</td>
<td>David Hinds</td>
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<tr>
<td>Stroke</td>
<td>Lora Swaffield</td>
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<tr>
<td>The Aphasia Handbook</td>
<td>Available from the Volunteer Stroke Scheme</td>
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<tr>
<td>Stroke Recovery Plan</td>
<td>Dr Langton-Hewer and Dr D.T. Wade</td>
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APPENDIX J

USEFUL ADDRESSES

Irish Migraine Association
Carmichael House
North Brunswick Street
Dublin 7
Tel.: (01) 872 4137
Fax.: (01) 872 4157
E-mail: info@migraine.ie
Website: www.migraine.ie

Irish Society for Autism
Unity Buildings
16 Lower O’Connell Street
Dublin 1
Tel.: (01) 874 4684
Fax.: (01) 874 4224
E-mail: autism@isa.iol.ie

Spinal Injuries Action Association
National Rehabilitation Hospital
Rochestown Avenue
Dun Laoghaire
Co. Dublin
Tel.: (01) 285 4777
Fax.: (01) 235 0955
Email: siaair@tinet.ie

Syringomyelia Self Help Group
Millmore House
Aughnamullen
Castleblayney
Co. Monaghan
Tel.: (042) 974 2102

Volunteer Stroke Scheme
249 Crumlin Road
Dublin 12
Tel.: (01) 455 9036
Fax.: (01) 455 7013

Action for Mobility
8 Elizabeth Street, Dublin 3
Tel.: (01) 8376333 after 6pm

Centre for Independent Living
Carmichael House
North Brunswick Street
Dublin 7
Tel.: (01) 8730 455
Fax.: (01) 8730 988

Disability Federation of Ireland
2 Sandyford Office Park
Dublin 18
Tel.: (01) 2959344
Fax.: (01) 2959346
E-mail: dfi@iol.ie
Website: ireland.iol.ie/~dfi/

The Equality Authority
Clonmel Street, Dublin 2
Lo-call: 1890 245545
Fax: (01) 417 3366
Email: info@equality.ie
Website: www.equality.ie

Forum for People with Disabilities
First Floor
21 Hill Street
Dublin 1
Tel.: (01) 878 6077
Fax.: (01) 878 6170
E-mail: inforum@indigo.ie

Irish College of General Practitioners
4-5 Lincoln Place
Dublin 2
Tel.: (01) 676 3705
Fax.: (1) 676 5850
E-mail: info@icgp.ie
Website: http://indigo.ie/~icgp/index.htm

National Rehabilitation Board
25 Clyde Road
 Ballsbridge
Dublin 4
Tel.: (01) 6684 181
Tel.: (01) 660 9935

People with Disabilities in Ireland Ltd.
Richmond Square
Morning Star Avenue
Dublin 7
Tel.: (01) 872 1744
Fax.: (01) 872 1771
E-mail: pwdi.ie
The Irish Neurological Alliance Standards of Care for People with Disabling Neurological Conditions (Progressive and Static) were compiled by the Irish Neurological Alliance in conjunction with the Elan Neurology Advisory Board. The make-up of that Board is as follows:

Dr Orla Hardiman  Consultant Neurologist, Beaumont Hospital (Chairperson)
Ms Jennifer Browne  Hospital Pharmacist, The Mater Hospital, Dublin
Dr Donal Costigan  Consultant Neurologist, The Mater Private Hospital, Dublin
Ms Jane Curtin  Account Director, Edelman Public Relations
Dr Mark Delargy  Consultant in Rehabilitation Medicine, National Rehabilitation Hospital, Dun Loaghaire
Dr Michael Dillon  Pharmaceutical Consultant, Dillon & Associates
Mr Michael Dineen  General Manager, Multiple Sclerosis Society of Ireland
Dr Joe Duggan  Consultant Geriatrician, JCMH, Blanchardstown, Dublin
Dr Tim Lynch  Consultant Neurologist, The Mater Hospital, Dublin
Dr Eamonn Mulkerrin  Consultant Geriatrician, University College Hospital Galway
Dr Padraig Murray  Consultant in Rehabilitation Medicine, National Rehabilitation Hospital, Dun Loaghaire
Professor Ciaran O’Boyle  Professor of Psychology, Royal College of Surgeons, Ireland
Ms Eileen O’Kane  Director, Parkinson’s Association of Ireland
Dr Veronica O’Keane  Consultant Psychiatrist, Beaumont Hospital, Dublin
Dr Brian Sweeney  Consultant Neurologist, University College Hospital Cork
Ms Aideen Walshe  Director of Marketing and Sales, Elan Pharma (Ireland) Ltd.
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