

## **A long term national health strategy**

Chronic disease has been a strong focus in recent health care strategic planning. Progressive neurological disease is a major and increasing contributor to the chronic disease cohort but has been overlooked in the recent focus to better meet the needs of people with chronic disease and the ageing population.

The increasing and complex needs of people with progressive neurological disease, particularly those with rapidly progressing, fatal disease such as motor neurone disease (MND) present a considerable challenge to national health strategy planning and service provision.

Health management for people with progressive neurological disease currently involves a number of state and federal government departments and funding bodies, including health, disability, ageing and palliative care. This leads to a confusing array of services and inconsistencies in delivery of essential services between different state and area health service administrations. Currently there is a 'hit and miss' approach to service delivery with the complex and sometimes rapidly changing needs of people with progressive neurological disease being poorly understood by both health care professionals and the community at large. Gaps in essential services can result in inappropriate admission to acute care or long term residential care which is traumatic for the person with progressive neurological disease and the family and costly to the community.

To avoid gaps in services and to address unmet need it is vital that a **national** approach be adopted to ensure best practice care and a less confusing system. Disease specific evidence based care pathways must be developed with customized plans of care to support the family and enable them to plan ahead.

Strategic planning for people with progressive neurological disease should also include:

- Building capacity within the medical, allied health, community nursing and community care workforce as this is an essential resource for maintaining independence and quality of life for this target population
- Better support for carers including increased financial support, more respite, education for carers to help them manage the changing needs of the care recipient, special support for ageing carers and a more informed and supportive workplace for carers
- Improved support for the whole family including counseling to minimize the impact of living with progressive neurological disease
- Access to aids and equipment in a timely manner
- Increased funding of NGOs representing people with progressive neurological diseases and their families. This will increase the capacity of these organizations to provide support, education, information and advocacy for people with specific neurological disease and their family and to educate care providers and the community at large about the needs and care of this target group
- Improved end of life care for terminal progressive neurological disease. The need also exists for a national approach to advanced care directives

The number of people living with progressive neurological disease is increasing due to the general ageing of the population, adverse environmental factors and improved treatment options. It is important to rectify the neglect of health care planning for this vulnerable sector of the chronic disease population and to have working strategies in place to address increasing unmet need.