

Strengthening communities, supporting families and social inclusion

Adult onset progressive neurological diseases cause complex levels of physical disability. Changing and complex need is a particular challenge in rapidly progressive, fatal diseases such as motor neurone disease (MND). Escalating dependency needs of the patient typically result in the loss of employment for both the person with the disease and the partner/carer. This leads to financial and emotional distress and social isolation for the person with the disease, the carer and family. These impacts have potential long term negative effects on the physical, emotional and financial well being of surviving family members.

Formal and informal support networks must work together to build social capital and better support families affected by progressive neurological illness and to facilitate their involvement within the community and the economic mainstream for as long as possible.

Formal support networks include:

1. Adequate provision of health and community care services. These services are essential to help maintain independence for the patient and quality of life for the patient and family.
2. Adequate levels of respite services are vital to enable the carer's continued employment and to help the carer sustain on going care within the home. The alternative - long term residential care - will incur significant cost to the community and predictably fails to meet the physical and emotional needs of the person with progressive neurological disease.
3. Education for the carer in managing the patient's changing needs.
4. A higher level of financial support for the carer
5. Improved availability of disabled access and transport facilities to facilitate continued community involvement.

Informal support networks include:

1. A more informed community with a better understanding of the needs of people with progressive neurological disease
2. Improved awareness and support from local community organizations, including local council, neighborhood, church, pastoral and ethnically based groups
3. Informed and supportive employers who will facilitate ongoing employment for as long as possible and who will offer better support to carers

To overcome the current level of confusion that exists towards state and federal based service provision it is vital that a **national** approach is adopted towards best practice care planning and consistent provision of essential services for people with progressive neurological disease.

The complexity of need within this target group requires a mechanism to ensure effective communication between all stake holders in care provision. **Effective coordination and integration** of both formal and informal support networks is essential to ensure optimal support and efficiency of service delivery.

Organisations such as Case Management Programs and the NGOs who represent this target group should be better funded and more empowered to fulfill this coordinating role. Neurologically based NGOs are well placed to offer disease specific information, education and support services from professional staff and volunteers.

Building capacity within these NGOs will facilitate increased education for both professional support networks and the general community. This will build social capital optimising both professional and volunteer support for families living with progressive neurological disease and diminishing their sense of social isolation.