

Services for people with long-term neurological conditions**Date**

Ongoing

Location

Hospitals, general practice & voluntary organisations throughout Greater Glasgow

Key Partners

GGNHSB planning department, hospital specialists, general practitioners and voluntary organisations.

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Summary of project and achievements

Innovative services for people with long-term neurological conditions such as brain injury, epilepsy, multiple sclerosis, Parkinson's disease and Huntington's disease are described here. Often the focus is on diagnosis and medical treatment, with patients and their carers being left to gather together for themselves the other forms of support needed to help them achieve a reasonable quality of life. Expertise is almost always concentrated in acute hospitals, with primary care and community services having little specialist knowledge of these conditions and therefore very limited ability to help. In Glasgow, the Health Board has brought together general practitioners, hospital doctors and nurses, voluntary organisations which represent people with particular conditions and local authorities to develop holistic systems of support which provide not only a high quality health service but which also address the many other factors which contribute to a meaningful and satisfactory quality of life.

Service developments

In primary care the 'chronic disease management' programme now includes epilepsy and multiple sclerosis. Members of participating primary care teams have received specialist training and will undertake regular surveillance of patients. On the hospital side, six nurse specialists have been recruited to improve services for patients with Parkinson's disease, epilepsy and multiple sclerosis. In addition, two physiotherapist specialists in multiple sclerosis have been appointed. The numbers and range of therapists in the community physical disability team (for adults up to 65 years of age) has also been substantially increased.

The voluntary organisations which provide support services for people with epilepsy, multiple sclerosis and Huntington's disease have each been provided with funding to develop a range of services. These include outreach therapeutic facilities (with transport) for people unable to leave their homes; information and counselling; a range of daytime activities (e.g. art therapy, theatre, tai chi); developing volunteering; programmes for stress and fatigue management; education of the public and professionals; developing links with other service providers; involvement of users in assessment of needs (e.g. by FOCUS groups); development of patient-centred outcome measures; and development of communication links between users and with professionals; and research.

Services for people with long-term neurological conditions (continued)

The New Opportunities Fund has recently provided resources to extend an existing clinical information system for Parkinson's Disease (PD) at the Victoria Infirmary to the four other hospital sites which have a PD service. It is hoped that this integrated system will improve surveillance of patients, reduce paper-work, facilitate communication between professionals and patients and provide useful epidemiological data. If successful, the aim is to extend the system to other neurological conditions.

Innovative aspects

- A coherent system of care for each client group with good coordination between the various service providers
- Specialist resources outside the hospital for people with long-term conditions. These will also benefit general practitioners as sources of specialist expertise to which they can refer patients with difficult non-medical problems.
- Increasing patient involvement in service development and in the management of their own care (the 'expert' patient).
- Transfer of some work and responsibilities from hospital consultants (mainly neurologists) to specialist nursing and physiotherapy staff.
- Promoting a culture of goal orientation (what interventions are intended to achieve in each individual) and evaluation (both quantitative and qualitative).

Conclusion

Considerable progress has been made in the development of customised and integrated services for people with a range of long-term disabling neurological conditions. Two important deficiencies however remain to be addressed. First there is a need, strongly expressed by patients and professionals alike, for an improved rehabilitation service for people with neurological disorders – particularly physiotherapy for those who are severely disabled. At present it is not possible to provide ongoing rehabilitation for such patients and the best that can usually be achieved is occasional short programmes. There also needs to be clearer definition of what forms of rehabilitation would be of greatest benefit, and to make greater use of self-help programmes, group therapies, physiotherapy assistants and exercise facilitators.

The second deficiency is that by focussing on major medical conditions, services for people with less common conditions such as muscular dystrophy and the ataxias have been relatively neglected. The development of more coherent services for these patient groups is currently being explored.