

17 March 2011

SERVICES FOR NEUROMUSCULAR CONDITIONS: MINISTERIAL RESPONSE TO STRATEGIC REVIEWS

In fulfilment of a commitment given to the Muscular Dystrophy Campaign, the Government commissioned the Scottish Muscle Network to undertake a strategic review of the services available across Scotland for those living with neuromuscular conditions. That report has been complemented by the Mackie Report on access to neuromuscular care and social care in Scotland, produced by the Cross Party Group on Muscular Dystrophy. The Government also made funding available to enable representatives of the Scottish Muscle Network to visit Denmark to look at aspects of services there that might inform the development of services in Scotland. The Network has now produced a report on that visit. In parallel with these pieces of work, the Government also funded the Network to undertake a project designed to explore how Self Directed Support (SDS) could improve personalised care for people with neuromuscular conditions, and to develop resources to promote the uptake of SDS within local communities.

A number of key themes emerge from the recommendations in these 3 reports, and the Government response is set out below.

Our starting point is that a great deal of work is already under way that will help with the development of services for those with neuromuscular conditions. It includes:

- investment through the National Delivery Plan (NDP) for Specialist Services for Children and Young People, which is funding neuromuscular services in each of the 3 Regional Planning Group areas. This investment enables multi-disciplinary teams to be broadened, to ensure specialist medical and nursing care is complemented by the full range of AHPs from physiotherapy to dietetics;
- Our investment in the national wheelchair and seating service, which is supporting the more timely provision of wheelchairs in a way that responds to people's needs at each stage in the progression of their condition. The clinical standards for wheelchairs and seating services, on which we have just been consulting recently, will also bring further improvements for those with neuromuscular conditions;
- We have amended the Scheme of Assistance Regulations under the Housing (Scotland) Act 2006 to provide a fairer and simpler scheme of grants for housing adaptations, with grants of up to 100% being available in particular cases;
- The funding we have provided for implementation of the review of clinical genetics, which directly addresses the needs of those with inherited neuromuscular conditions; and
- Our work on Getting it Right for Every Child, which is developing new approaches to the co-ordination of multi-agency services, with a clear focus on the needs of the individual.

The Scottish Muscle Network itself has been undertaking a valuable programme of service improvements, in particular in relation to: the development of standards based on international experience; the creation of agreed care pathways, including transitions; and the provision of information to families. The Network has also supported patient, service use and third sector involvement in its steering group and working sub-groups. Its efforts are already paying dividends in terms of increased life expectancy and improved quality of life.

The Network approach is particularly suited to the difficulties faced in providing specialist services for a rare group of disorders across a large geographical area, in particular the problems posed by travelling for those living in remote and rural communities. The Government therefore fully endorses the Managed Clinical Network approach for the management of rare and complex conditions. Key to this model is the refinement of the pyramid of care through universal, secondary, tertiary and quaternary services, with clear and well-developed referral pathways between services. The Government therefore recognises the Network as the main vehicle for taking forward the recommendations in the 3 strategic reports. We have accordingly asked National Services Division, as commissioner, to ensure the Network has the support and resources it needs to discharge this role. We strongly endorse the proposed strengthening of engagement between NHS Boards, local authorities and the Regional Planning Groups.

One of the most pressing issues identified in the strategic reports is the need to put on a secure footing the funding by the NHS of the 2 Care Advisers who have been supported up until now by the Muscular Dystrophy Campaign. We accept the vital role the Care Advisers play, especially at times of crisis, and fully support the need to secure the funding of the present posts. This is in line with the commitment given by the Cabinet Secretary for Health & Wellbeing following her participation in the Muscular Dystrophy Campaign's annual conference last autumn. We therefore welcome the assumption of responsibility for this funding from 1 April 2011 by NHS Greater Glasgow & Clyde and NHS Lothian. These posts are, however, part time, and we now understand that, in keeping with recent developments in neuromuscular services outlined above, the Scottish Muscle Network believes the role of the care advisor should be re-defined as Specialist Neuromuscular Nurses. The Network argues that 3 full-time posts are needed to cover the whole country adequately. At my request, the Network is drawing up a job description for these posts, and we will discuss with those responsible for planning services in the NHS how they could be funded on a sustainable basis.

The Network is now also recommending the creation of 2 social work adviser posts for patients and families with complex neuromuscular conditions. These advisors, working specifically with adolescents and young adults up to the age of 40, would be able to address in particular the difficulties encountered in setting up complex care packages which are designed to meet the personalised health and social care needs of individuals. A more efficient process for accessing funds, which should already be available within local authority budgets, arising from the recently published SDS strategy, will bring a number of advantages. It would benefit not only the individual, but also reduce unscheduled acute hospital admissions, prevent delayed discharges from hospital, and achieve a more efficient use of the clinical time and resources that currently have to be devoted, inappropriately, to the creation of care packages. We are aware that similar conclusions about the need for such an approach are emerging from the work of the Single Gene Complex Needs project. We have therefore asked the Network to develop its thinking on the nature of these posts, in particular whether they are expected to take on a national training and advocacy role.

The Scottish Muscle Network's Self Directed Support (SDS) work has identified particular difficulties for service users and their family carers in accessing direct payments, largely because of a lack of focus on, and lack of knowledge about, neuromuscular conditions. There is evidence of people across Scotland being on waiting lists for considerable periods, and requiring assistance and advocacy in their dealings with local authority social work agencies. The Danish experience of using SDS models to provide appropriate and adapted accommodation, access to further education and employment, involved focussed and targeted transition practice. This has much to commend it, in raising aspirations and life chances for individuals and family carers. The 'Talking Points' outcome work advocated in the SDS strategy would enable considerably improved outcomes for service users. We have given a commitment to explore the potential of SDS to address complex care cases and packages.

The strategic reports raise a number of issues about the need to develop essential specialist services in a number of key clinical areas. First and foremost among these is respiratory care. The Network's visit to Denmark has highlighted the value of specialist respiratory care, including invasive ventilation (tracheostomy) in delivering real improvements in life expectancy and quality of life for people with neuromuscular conditions. We have agreed to work with the Scottish Thoracic Society to promote awareness of the benefits of this approach, and to build the structures that will make it easier to access to such a service. We shall also raise this issue with those working in the complex respiratory Managed Clinical Networks that are being developed at regional level as part of the National Delivery Plan for Specialist Services for Children and Young People. It is critical that this work is co-ordinated with adult respiratory services across Scotland to ensure that specialist care is available to all, with seamless transition from paediatric to adult services. To take this forward, we have already asked the National Advisory Group for the respiratory Managed Clinical Networks that we've pump-primed in each NHS Board to make links to these regional Networks.

There are also specialist issues in relation to the cardiac aspects of neuromuscular conditions that again have a real bearing on life expectancy and quality of life. We welcome the closer working that is already taking place between the Scottish Muscle Network and FANS, the Familial Arrhythmia Network Scotland, which now covers conditions such as the cardiomyopathies. It's a direction of travel we set out in our 2009 Heart Disease and Stroke Action Plan. This will achieve integrated working between cardiologists and the clinicians responsible for the general care of those with neuromuscular conditions.

The other main clinical issue identified in the reports is the role of specialist physiotherapists. We have already provided funding, in the wake of the review of genetics services, for a specialist physiotherapist post in the east of Scotland, to complement the work of the consultant in inherited neuromuscular conditions whose post is funded from the same source. Strengthening the number of specialist physiotherapists has been a particular focus of the funding made available to implement the National Delivery Plan, with funding now secured for a second paediatric physiotherapist for the West of Scotland, and 22.5 hours of a specialist neuromuscular children's physiotherapist as part of the north-east Scotland neurology MCN. The strategic reports also highlight the need to develop specialist knowledge of neuromuscular conditions amongst physiotherapists in general. As a way of doing so, we are encouraging the Scottish Muscle Network to develop links with the Association of Chartered Physiotherapists in Neurology, which has a network of 17 regional representatives who organise regular educational programmes across the country. We will also explore the role that could be played by those responsible in each NHS Board for taking forward the National Delivery Framework for Adult Rehabilitation.

The reports also emphasised the importance of improving knowledge of neuromuscular conditions within Primary Care. We have encouraged the Scottish Muscle Network to take up this issue with NHS Education for Scotland and the Scottish Council of the Royal College of General Practitioners. We also undertake to explore the potential for implementation of our 2010 Delivering Quality in Primary Care Action Plan to raise awareness of neuromuscular conditions within the Primary Care Team, in particular in the light of the care pathways that the Network has been developing.

We believe that taking these actions in response to the 3 strategic reports will indeed allow them to act as a real catalyst for the systematic improvement of neuromuscular services across the whole Scotland. That in turn will lead to further improvements in life expectancy and quality of life that will stand comparison with the best achieved anywhere else in the world.



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