

MNDA Neuro Wheelchair project - The right chair at the right time

What is Motor Neurones Disease?

Motor neurone disease (MND) is rapidly progressing neurological condition in the majority of cases is always fatal. The disease may commence at any age in adult life, the peak age of onset at 55 to 60 years, affecting twice as many men as women.

People with MND will, in varying sequences and combinations, lose the ability to speak, swallow and use of their limbs; the most common cause of death is respiratory failure. The individual often will remain mentally alert as they become trapped within a failing body, although some people do experience dementia or cognitive change. There are about 5,000 people living with MND in the UK. Half of people with the disease die within 14 months of diagnosis at present there is no cure.

Due to the rapid progression of this condition it is imperative to provide timely, appropriate and anticipatory services for people with MND that are integrated and work together. As a relatively rare condition health and care professionals, often struggle to understand and respond to the needs of people with MND in a timely manner. Current prescription criteria within wheelchair services can cause problems for people with MND as at the time of assessment they do not meet the criteria for the provision of a more complex chair.

The Neuro power wheelchair project

The MND neuro power wheelchair project is currently funded by the Department of Health through their Innovation, Excellence and Strategic Development Fund for 2 years. This commenced in 2013 and will run to 2015.

Project Aims

1. To provide a responsive service in respect of assessments and provision of powered wheelchairs for people with MND at three centres through the recruitment of three specialist therapists who will only assess people with MND
2. Work in conjunction with three leading wheelchair manufactures, to develop a specific prescription form within the NHS range of EPIOC's (Electrically Powered Indoor/Outdoor Chair), that will meet the current and on-going needs of people with MND (and other rapidly progressing neurological conditions) at an optimum cost for statutory provision and with a short lead time.

The expectation is that these two elements will allow people with MND to be seen rapidly and receive the right wheelchair at an early stage, which is suitable to meet their needs as their disease progresses.

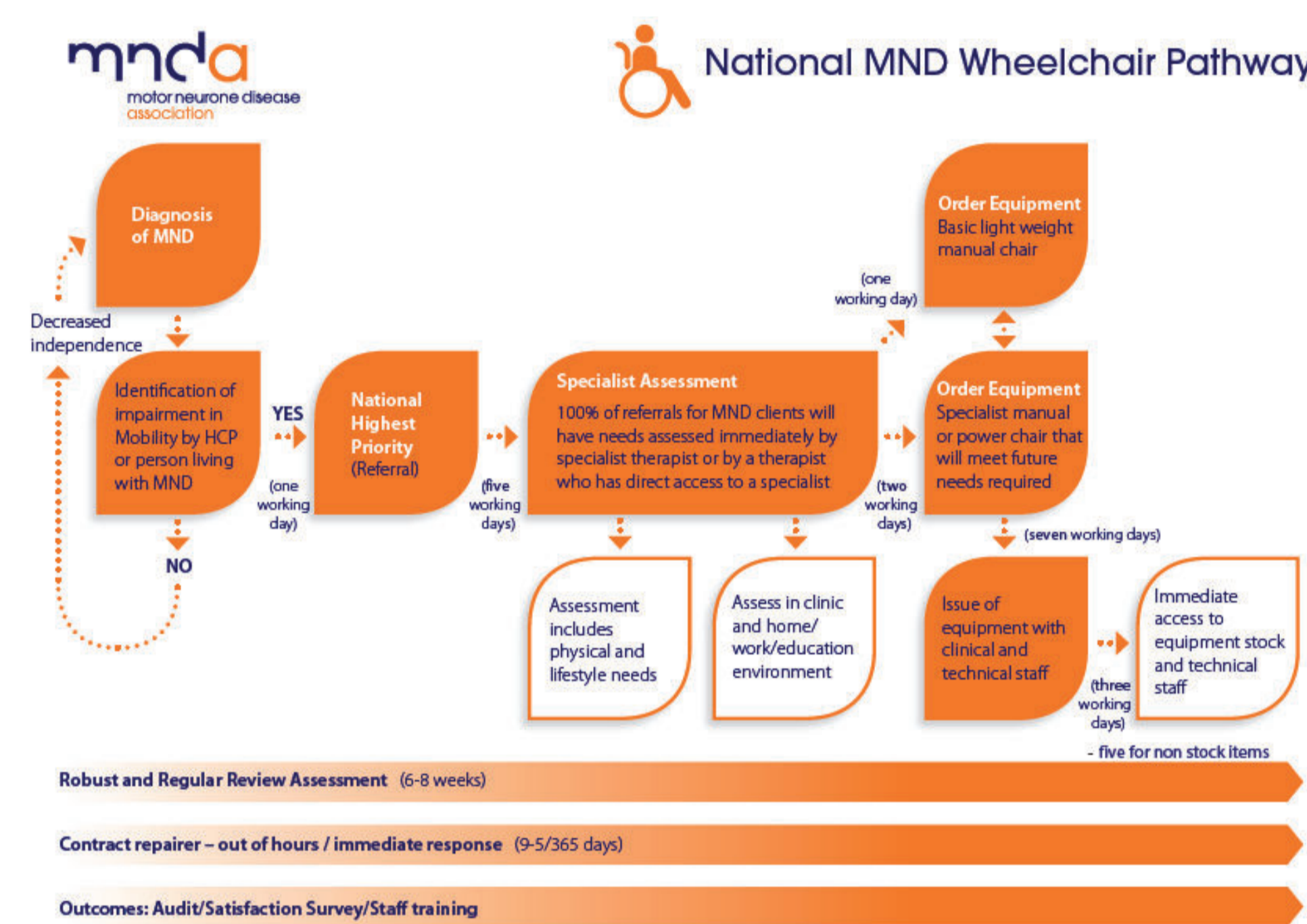
Wheelchair therapists

Three Wheelchair therapists have been appointed into the project across England, based in Oxford; Leeds and Surrey working with MND care centres.

The role of the therapists is:

- To make links with local and regional wheelchair centres. Support in delivering timely and appropriate assessments and wheelchair provision to people with MND. To be a resource to other professionals as and when required.
- Support in service development and promote the use of advanced prescription.

- To work with three leading wheelchair manufacturers to develop and review the Neuro power wheelchair prescription to ensure the chairs and features continue to meet the needs of people with MND.
- To make links and develop pathways to ensure people with MND get timely access to appropriate communication aids and environmental controls, which can then be intergrated and mounted onto the wheelchair.



Wheelchair Specification and development of the Neuro power wheelchair prescription

The MNDA and therapists have work with 3 leading wheelchair manufactures (Invacare; OttoBock and Sunrise) to develop the neuro power wheelchair prescription.

Prescription Specification to manufacturers

1. EPIOC Wheelbase which is small and compact so it will fit around the persons home.
2. Tension Adjustable Back with a padded back support to protect boney prominence. Which will accommodate upper kyphosis and provided lateral support.
3. Electric Tilt in space - To support posture; prevent sliding. Improve respiratory function.
4. Padded/supportive arm rests - adjustable in positioning to support forearm and to facilitate supported driving.
5. Headrest - angle adjustable; multi positional.
6. Footplates and hangers - Multi angle adjustable.
7. Seat board - To allow appropriate pressure cushion to be provided.
8. Controls - Adaptable and multi positional.
9. Have the electronic capability to interface with AAC devices such as smart phones; tablets; and environmental controls as well as being able to control the wheelchair.



10. Trays and mounts for communication aids and other equipment.



Service review & on-going development

Service Audit

The Leeds therapist Chris Orr undertook and audit of wheelchair provision for people with MND. The audit reviewed time from referral to provision of the wheelchair from 2011;2012;2013 prior to the appointment of the specialist MND wheelchair therapist. Data since the appointment is then used as a comparison. The data shows that in the majority of cases there has been a significant decrease in time from referral to provision of the wheelchair required. There has also been a decrease in wheelchair re-provision as people with MND are being provided with a wheelchair that meets long term needs.

Steering groups

The three wheelchair therapists have organised local steering groups to progress the work of the neuro power wheelchair concept across statutory services. The steering groups develop local and regional links with wheelchair services; local authorities, communication aid teams and environmental control teams.

The steering group aims to share good practice, identify challenges and develop clear pathways for people with MND to ensure they have the right provision of equipment at the right time.

Wheelchair prescription review

The prescriptions have been reviewed with the three manufactures following feedback from practitioners.

Further areas identified for development is a standardised range of mountings and trays for ventilators, communication aids, suction machines etc. These need to be easy to fit and remove and adaptable to different products.

Person experience review

An outcome questionnaire has been developed for people who are involved in the MND wheelchair service to evaluate the service provide by the therapists and the wheelchair provided. The aim is to establish how the wheelchair provided has impacted on their independence and quality of life.

Conclusion

The project is currently on-going the overall aims of the project are progressing.

The project aims to reduce the number of assessments for wheelchair provision as the right chair is provided at the right time with regular robust review resulting in:

- Improved patient and carer experience.
- Reduced cost and value for money.
- Timely provision of equipment.