

Aspire's Response to 'Helping to Deliver Patient Led Wheelchair & Special Seating Services with the support of this Patients Charter'

Aspire is a national charity working to support people with spinal cord injuries. We focus on offering practical services and guidance to ensure that those we work with have every opportunity to live independently. Aspire welcomes this opportunity to provide feedback on the Patients' Charter which is looking at the issue of "Helping to deliver Patient Led Wheelchair & Special Seating Services" proposed by the Associate Parliamentary Limb Loss Group, the All-Party Parliamentary Group for Spinal Cord Injury and the All-Party Parliamentary Group for Muscular Dystrophy.

The User will assess the service by its effectiveness – the extent to which, and the quality with which, it meets Users' needs. Effectiveness requires the Services to be organised and run around the health needs of individual Users, rather than for the convenience, budgetary or otherwise.

Aspire fully agrees that the effectiveness of the Service should be assessed by its ability to meet the Users' needs. However, we feel that unless those needs are adequately defined, there will always be scope to 'bend' the success of any given Service. Too often, 'health' and 'clinical' needs are taken to mean merely that the User can operate the wheelchair without detriment to their short term physical health, completely bypassing the social needs, long term physical health (including shoulder damage) and the mental health of Users who do not have a wheelchair that meets these additional requirements.

The User has first-hand knowledge of his/her requirements for independence in day-to-day living, and needs assurances that his/her views will be taken into account.

Aspire recognises the benefit of taking into account the knowledge of the 'expert User' and firmly believes that their views should be taken into account. We would emphasise, though, that for a newly spinally injured User, and indeed many other Users who acquire a condition necessitating the need for a wheelchair, they will not yet become "expert" in their own requirements for some time after discharge from hospital. Extra caution must be taken to ensure that such Users are given additional assurances and guidance to guarantee that what is prescribed for them is going to meet their needs.



... each User should be entitled when his/her needs change to request review by his/her clinical rehabilitation team.

Aspire fully welcomes and supports this point. As people are living longer with Spinal Cord Injury as a result of better life expectancy, the likelihood of newer conditions and complications developing is ever more prominent. Functionality, independence and physical wellbeing can change rapidly with both positive and negative effects and must be managed appropriately. Therefore Users having the entitlement to request reviews from their clinical rehabilitation teams is crucial in ensuring that the User's needs are met at different stages of their life. Spinal injury Centres offer a life-long service to manage these ongoing changes and there should be no "waiting times" to meeting the need for changes in the provision of different wheelchairs or seating.

Prescription must be undertaken by an appropriately qualified Health Professional...

For those who are spinally injured and undergo rehabilitation in a Spinal Injury Centre, prescription of their first wheelchair for use during their rehabilitation in hospital and following discharge will be carried out by a specialist spinal injury Occupational Therapist. Too often what is prescribed for them is not then accepted by their own wheelchair service and another assessment has to be carried out. Whilst Aspire agrees that prescription must be undertaken by an appropriately qualified health professional, we would like it confirmed that this health professional should not have to be directly employed by the wheelchair service. Given the in-depth knowledge of their clients' abilities and needs we feel that a prescription completed by the specialists at a spinal unit would be based on a more complete picture of the person's needs. Occupational Therapists at a spinal centre would have a greater understanding of the potential changes in functionality, skin management and the overall physical wellbeing of the User's needs and knowledge of the wheelchair and seating that would best suit them.

If, because of lack of funding or pressure on resources, the most appropriate solution cannot be provided, the reasons must be fully documented by the Health Professional in a written Report of Prescription and circulated to all concerned.

Aspire welcomes the need for written reports justifying why the appropriate wheelchair has not been prescribed. These cases must be logged as an unmet need, and this data made available both locally and nationally.

Resultant best practices should be shared nationally through the Knowledge Sharing Network for People with Complex Physical Disabilities.

Aspire welcomes the need to share this information as it can empower staff to meet the needs of Users by having a strong pool of resources and information. This information can demonstrate what has worked best in other parts of the country, therefore leading staff to become better equipped in matching any acute needs that Users may have.

Krupesh Hirani

Policy and Research Officer

Aspire
Wood Lane
Stanmore
Middlesex
HA7 4AP

krupesh.hirani@aspire.org.uk

020 8420 6702

