Statement on Tetraplegia

While the number of people living with spinal cord injury (SCI) in the UK who rely on care support is relatively small when compared to the total number of people living with long-term conditions who rely on care support, those with SCI generally require substantial levels of care in order to maintain their health, well-being and independence and avoid potentially costly and life-threatening complications.

However it is not widely understood that SCI is unique amongst long-term conditions in three significant ways:

1. SCI results in a unique combination of the loss of motor, sensory and continence function. In other words it results in loss of movement, feeling and the ability to control bladder & bowel function. No other long-term condition combines all three of these elements together simultaneously.

2. With complete SCI it is possible to predict with a high degree of accuracy the level of health care intervention an individual will need to stay healthy (and avoid potentially costly and life-threatening complications) from the neurological level at which their spinal cord is damaged, as described by the corresponding vertebra or vertebrae. This direct comparison is not possible with any other long-term condition.

3. SCI is a non-improving condition, so it does not fluctuate in the same way that other neurological conditions do. Therefore once rehabilitation is completed and the individual's health care needs have been established they are very unlikely to decrease, in fact they will increase over time with complications brought on through ageing with the condition. (Note: the term "non-improving" should not be confused with or interpreted as meaning "stable" because potentially life-threatening complications can occur unpredictably and very quickly without appropriate and timely management of the condition).

In order to assist assessors in understanding the effect of cervical spinal cord injury resulting in Tetraplegia and the health care needs that arise out of it the British Association of Spinal Cord Injury Specialists (BASCIS) and the Multidisciplinary Association of Spinal Cord Injury Professionals (MASCIP), the bodies representing health professionals working in the field of spinal cord injury, have agreed the Statement on Tetraplegia (as presented on the following page) in respect of NHS Continuing Healthcare.

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Statement on Tetraplegia

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British Association of Spinal Cord Injury Specialists (BASCIS)

Multidisciplinary Association of Spinal Cord Injury Professionals (MASCIP)

Spinal Injuries Association (SIA)

Date

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Statement

Spinal Cord Injury resulting in tetraplegia is a complex condition that involves all body systems and has complications which are unpredictable and potentially life-threatening in nature. Managing the condition and preventing these complications requires a dedicated care routine which includes frequent (at least hourly) daytime interventions and unpredictable additional care at night.

Accommodations need to be made for lifestyle and for state of health/wellbeing. Individuals with tetraplegia who are unwell e.g. with chest or urinary tract infections, pressure ulcer or otherwise requiring bed-rest will require a higher intensity of care than at other times.

Potential complications include autonomic dysreflexia (an unpredictable, life-threatening condition producing an abrupt onset of excessively high blood pressure with risk of inducing stroke, which is unique to people with a spinal cord injury of T6 or above), impaired ability to regulate body temperature (poikilothermia) and inability to adjust clothing/bedclothes in response, chest infections (needing carer-assisted coughing), urinary tract infections (leading to blocked catheter, septicaemia), unawareness of pulled/shifting indwelling catheters, incontinence (urinary and faecal), spasticity (resulting in increased pressure ulcer risk and risk of falls), and an inability to turn themselves or adjust sitting posture to relieve skin pressure independently rendering them highly susceptible to pressure ulcers. These complications can arise unpredictably and may require immediate life saving assistance/management within minutes. Optimal management regimens can minimise the occurrence of complications and prevent avoidable hospital admissions, but they cannot permanently reduce or remove the risk or the underlying health needs, which may still occur and require immediate intervention.
It is the opinion of both the British Association of Spinal Cord Injury Specialists (BASCIS) and the Multidisciplinary Association of Spinal Cord Injury Professionals (MASCIP) that the primary care needs of individuals with tetraplegia are health needs. A similar view was expressed by the Court of Appeal in the case of Pamela Coughlan, an individual with C5/6 complete tetraplegia. The Department of Health’s National Framework guidance, whilst cautioning against drawing generalisations about eligibility for NHS continuing healthcare, advises that:

"CCGs should be aware of cases that have indicated circumstances in which eligibility for NHS continuing healthcare should have been determined, and where such an outcome would be expected if the same facts were considered in an assessment for NHS continuing healthcare under the national framework (e.g. Coughlan...)."

This has all the more force, since the Court of Appeal in Coughlan considered that she “...needed services of a wholly different category...” (to that which social services could lawfully provide). BASCIS and MASCIP consider that in such assessments, individuals with tetraplegia, whose paralysis and health needs are comparable to or greater than those of Coughlan (an individual with a C5/6 complete tetraplegia) should be eligible for NHS Continuing Healthcare funding, irrespective of age.

Appendices


Managing Spinal Cord Injury: Continuing Care (2006); Edit. P. Harrison RGN, MA Ed. Available at www.spinal.co.uk

1 R v. North and East Devon health authority ex p Coughlan (1999)
   http://www.bailii.org/ew/cases/EWHC/Ch/1999/1911.html


Notes

It should be noted that this Statement is only applicable in England**. The National Frameworks for NHS Continuing Healthcare differ in other parts of the UK, and as NHS Continuing Health Care in Scotland, Wales and Northern Ireland is a devolved matter this Statement is not applicable to Scotland, Wales or Northern Ireland.

Signatures

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Useful links

http://www.bascis.org.uk  http://www.mascip.co.uk  http://www.spinal.co.uk