Neurological Alliance of Scotland response to the draft standards for Care of Older People in Hospital

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The Neurological Alliance of Scotland (NAoS) welcomes the Care of Older People in Hospital draft standards. In general, we feel the Standards are clearly written and mostly free of jargon. We support the implementation of standards to help support improvement in hospital care for older people in Scotland.

We accept that these standards only apply to older people but feel that this may be somewhat problematic as neurological conditions can affect people of any age. Some conditions, such as dementia and Parkinson's are much more likely to affect older people but can also affect younger adults. The highest rates of epilepsy are amongst older adults and children, but it affects people of all ages. MS is the commonest disabling condition of people of working age, but more than one in three people living with MS in the UK is aged over 60 (ref: http://www.mssociety.org.uk/sites/default/files/MS%20in%20the%20UK.pdf). Adults of any age can develop Huntington's, Progressive Supranuclear Palsy (PSP) or MND though prevalence increases with age.

We have some brief comments in relation to some of the standards and related criteria set out and have therefore listed them below rather than using the response form provided.

Standard 1 Involving Patients – What Matters to me.

The Neurological Alliance of Scotland supports the premise of Standard 1 and related criteria. As previously mentioned however, we believe that care in line with these standards should be available for any adult in hospital who is frail or has complex needs, whatever their age. They are particularly relevant for people with degenerative neurological conditions.

We would advocate that specific criteria relating to the involvement of carers is also included within Standard 1.

Furthermore, older people with degenerative neurological conditions may well have cognitive and communication difficulties and may need advocacy / communication support to enable them to make their wishes known. Therefore we would suggest that Criteria 1.1 is expanded to:

All older people will have the opportunity to **and be supported where necessary** to say what and who matters to them.

Standard 2 Consent and Decision Making

We agree with the criteria set out in standard 2 and feel that the principles are good. We have some concern that the language used is however overly legalistic and that the criteria should do more than just reiterate that care teams should comply with relevant legislation.

We also think that further consideration and clarity should be given to defining what constitutes capacity. In relation to some neurological conditions (e.g. Multiple Sclerosis and Parkinson's disease), capacity may fluctuate and is therefore not an absolute concept. People may have the capacity to make some decisions but not others. We would also advocate that people's views are actively sought and considered by the care team even in instances where the person does not have legal capacity.

We would like to see the language used regarding carers in criteria 2.5 being reframed to match language later in the document. Rather than being referred to as a 'legal proxy' we would support explicit recognition of the insight and information that carers and family members are able to offer to care teams and would suggest that language similar to that used in Standards 9 & 13, in which carers are recognised as equal partners in care is used.

Finally we believe that the inclusion of end of life care and support should be included in this standards criteria.

Standard 3 Maintaining Dignity and Privacy

We support the rationale and criteria of standard 3. However once again we believe that carers should be included within this standard to ensure that specific needs of the older people are understood.

We also believe it would be useful to include some coverage of dignity and privacy for individuals and families during discussions about treatment and care, and at end of life (for example, private facilities, discretion of staff etc.)

Standard 4 Patient Pathways and Flow
Standard 5 Skills Mix and Staffing levels
Standard 6 Initial Assessment

Effective patient flow is crucially important for people with very complex health care needs such as those with a degenerative neurological condition such as MND, Parkinson's disease, Huntington's disease and dementia. We believe that it is important that staff who specialise in these conditions are involved in decision making and ongoing care in all parts of the care pathway and that appropriate training and information regarding complex neurological conditions is available to all staff.

We believe that Standard 4 should state the importance of avoiding Boarding for people with particularly complex care needs such as those of people with degenerative neurological conditions. The care needed by people with degenerative neurological conditions will involve a range of expertise such as managing symptoms, mobility and communication issues and managing often complex medication needs (e.g. anticonvulsants / PD drugs/ MS disease modifiers etc.).

We also feel that it will be important to state that staff caring for people with complex neuro conditions should contact their specialist MDT (consultant, nurse etc.) for advice and guidelines on care for rarer conditions (for example Huntington's Disease and Motor Neurone Disease).

We also believe that the processes referred to in criteria 5.5 should be more clearly defined.

Standard 7 Care Planning and Medicines Arrangement

We welcome the criteria set out in standard 7 and feel it is appropriate.

We believe criteria 7.2 should also state that for high risk conditions like Parkinson's disease, medication changes must be discussed also with the person's specialist team

We would also support the role of carers being made explicit in Standard 7. Criteria 7. 1 should mention involving the carer where patient has given permission to do this and similarly 7.5 and 7.6 could recognise that carers should be involved in discussion on post discharge medication, explicitly acknowledging that carers often have role in supporting people with medication.

It may be worth also considering a system by which older people who have high risk medications are identified on admission. For example medication administered at the right time and dose is crucial for people with conditions such as Epilepsy and Parkinson's disease and staff should be aware of the importance of this.

Standard 9 – Rehabilitation

We note that rehabilitation is often understood as having outcome of improvement or independent living and would like reference to its importance for degenerative neurological conditions in regard to accommodating loss and reduction of function

We suggest it would be helpful to reiterate that people should not be denied access to rehabilitation on the basis of age.

Standard 11 Assessment and decline prevention

We are supportive of assessment on admission of cognitive functioning. Cognitive impairment of varying degree is characteristic of many neurological conditions. It is important however that this standard also takes account of fluctuating cognition and the effect of medication on cognitive functioning.

We would also suggest that paragraph 2 of the rationale makes reference to also taking account of people's expressive communication needs because problems with speech are commonly found in neurological conditions.

Standard 14 Depression

We agree with the rationale and criteria set out in Standard 14. In the case of neurological conditions, mental health issues such as depression and anxiety are common and are symptoms of the condition. We therefore believe it important that management of mental health issues should be in consultation with the person's specialist team where relevant.