Specialist Nursing Home Care for People with Complex Neurological Disability: Guidance to Best Practice

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The British Society of Rehabilitation Medicine is the Society which represents the specialty of Rehabilitation Medicine. It promotes an understanding of the specialty through the education and development of clinical guidelines and standards.

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Specialist Nursing Home Care for People with Complex Neurological Disability: Guidance to Best Practice
Working Party Membership

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The majority of people with severe physical or cognitive disabilities receive their nursing care in private institutions that operate at a distance from the NHS. This document, which is the work of a working party of the British Society of Rehabilitation Medicine, focuses on the management of younger adult patients within these institutions. Many of such patients will have survived a neurological catastrophe with a life expectancy of several decades. Some may make significant further improvement and others, with very severe impairments, are at great risk of complications from their condition and are likely to gradually deteriorate. It is vital that these people are managed in an institution that can meet their needs, and that these institutions deliver a good standard of care commensurate with the fees they are charging.

This document describes the processes of slow stream rehabilitation, complex disability management and the palliative care of severely impaired neurological patients and outlines the facilities and protocols that are needed to support this area of care. It introduces a way of categorising both the complexity of these patients' needs and levels of Specialist Nursing Home (SNH), and draws up a matrix whereby the commissioners of services, and the homes themselves, can make an appraisal of the service that is being offered. It describes some early research into the management of such patients in SNHs and hopefully will provide a focus for further research and clinical development with the aim of improving standards in this expanding and expensive area of healthcare.

Executive Summary

Specialist Nursing Homes (SNHs) are likely to play an increasingly important role in the continued management of patients with complex or profound disability following brain injury or progressive neurological disease. Although this work is mainly practised in the private sector it is largely commissioned by the NHS and needs a defined funding stream. This document describes this area of healthcare, making recommendations with reference to evidence where this is available.

This document does not deal with the management of learning disability or primary psychiatric disorders but addresses the wide range of physical, communicative, cognitive, behavioural and psychosocial problems encountered by SNH patients with complex neurological disability. Recommendations are made for both units that deal predominantly with physical disability (PhysD) and those that deal predominantly with cognitive and behavioural (CB) problems.

Specialist Nursing Homes are categorised in section 3 into

- Level 1 highly specialist units that manage patients with highly complex 'Category A' PhysD or CB needs
- Level 2 units that deal with less complex 'Category B' needs. These are distinguished from non-specialist
- Level 3 care homes that provide 'Category C' PhysD patients with only standard nursing care and 'Category C' CB patients with only standard precautions.

The descriptive categorisation of patient needs into categories A-C can be supported by the use of scales, in particular the Northwick Park Care Dependency Scale (NPCDS) and the Rehabilitation Complexity Scale (RCS). An adapted version of the RCS, the RCS-SNH, is introduced as a measure of case mix and complexity of care within the SNH setting. The level of care within a SNH is classified in section 3 into four levels from 'basic' to 'very high' using these scales with corresponding indicative tariffs, which should make these scales valuable as commissioning tools.

The care of patients in a SNH is predominantly a health activity and is described in section 2 along three main pathways:

- *Slow stream rehabilitation* - working towards specific outcome goals over a prolonged period with often the aim of returning to live in the community or moving to a less specialist setting
- *Complex disability management* - characterised by the maintenance of health and function and avoidance of complications in the face of severe impairments and activity limitation. Such patients are often, but not always, viewed in England as eligible for NHS Continuing Health Care (CHC)
- *Neuro-palliative rehabilitation or end of life care* - which is focused on relieving symptoms and distress, and is provided at the interface between Rehabilitation Medicine and Palliative Care.

Standards are recommended for the provision of this specialist healthcare for patients of varying complexity of PhysD and CB needs. These are listed in section 4 under the titles of:

- Nursing and medical care
- Access to facilities and therapies
- Rehabilitation programmes, goals and outcomes
- Assessment, coordinated care, communication and discharge planning
- Family and staff support
- Legal issues
- Advanced care planning and end of life care.

Guidance is also offered in section 3 on staff recruitment, complex seating, accessing NHS services and facilitating patient autonomy and well-being. It is recommended that both Rehabilitation Medicine, and nursing and therapy trainees are offered specific tuition and experience in SNH healthcare and that further research is undertaken to inform these clinical recommendations. Within the limits of the evidence that is available, it is hoped that this guidance will enhance both the commissioning and the provision of care to this vulnerable and expensive group of patients.

1 Introduction

1.1 Efficient use of acute hospital facilities and post-acute rehabilitation requires the timely step down of care to less intense provision as the patient's condition stabilises. Some severely impaired patients benefit from transfer to a nursing home which can provide:

- an enriched and more homely environment
- a lower risk of hospital acquired infection
- care from long term and familiar staff with whom they can establish relationships
- opportunities for socialisation with both residents and staff
- a chance to re-establish family relationships after a long hospital admission.

1.2 In many areas of the country certain nursing homes have become specialist (SNH) and have developed a high level of expertise in specific areas. These units manage patients who have a continuing complex or profound disability and who are discharged from hospital with very extensive care needs. They may also admit patients with progressive conditions, or stable conditions with age related decline, whose needs have become complex and who can no longer be managed in the community.

Table 1
Conditions giving rise to complex and profound disability requiring Specialist Nursing Home Care
(derived from Specialist Services National Definitions Set 3rd Edition 2010)

Sudden onset conditions	• acquired brain injury due to any cause including trauma, severe stroke, subarachnoid haemorrhage, meningitis, encephalitis, vasculitis, complications of surgery • spinal cord conditions* • combined brain and spinal cord injury • peripheral nervous system conditions eg Guillain-Barre syndrome • multiple trauma
Progressive and intermittent conditions	• neurological and neuromuscular conditions (eg multiple sclerosis, motor neurone disease, Huntington's disease, muscular dystrophies, inherited metabolic disorders) • severe musculoskeletal or multi-organ disease (eg rheumatoid arthritis with neurological complications) • physical illness complicated by psychiatric or behavioural manifestations
Stable conditions (with/without degenerative change)	• congenital conditions eg cerebral palsy or spina bifida in children or adults • following previous neurological injury Many of these conditions may remain stable for years but subsequently progress with accrual of problems due to age related change or other secondary complications.

* The majority of young patients with acute spinal injury can be discharged home. Older patients, or those with comorbidities or progressive conditions, are often considered for SNH care

1.3 This document will focus on the SNH management of patients with neurological disease as these patients often have difficulties with thinking, communicating and behaving, and their care can be particularly challenging. Patients with a diagnosis of neurological trauma or multiple sclerosis comprise only 4% of the care home population,[1] but they represent a group with longer than normal lengths of stay and whose care is particularly expensive. Costs are often in excess of £1,200 a week, reach £2,200 a week in units managing challenging behaviour and up to £4,500 a week in units offering ventilation. Commissioners may seek less expensive provision but this can place such patients at risk of complications[2] and lead to increased future health costs.

1.4 Headway, the brain injury association, has developed an Approved Provider Scheme which offers an assessment of nursing homes with specific reference to how the institution meets the needs of patients with brain injury and their families. This focuses on the provision of meaningful activity and family support, rather than addressing medical and nursing needs.

1.5 This document addresses the cognitive and behavioural needs of neurological patients, as well as their physical needs, and recognises that SNHs often specialise in either cognitive/behavioural (CB) or physical disability (PhysD) care. It does not, however, address the management of patients with a primary psychiatric condition or congenital learning disability.

1.6 Standards of care for this patient group are defined within Quality Requirements 7–11 of the National Service Framework (NSF) for Long-term Conditions (2005)[3] comprising:

- equipment and accommodation
- personal care and support
- palliative care
- supporting family and carers
- care in other health and social care settings.

1.7 In addition there is an under recognised need in some of these patients for a continued programme of specialist, goal directed, slower stream rehabilitation (Quality Requirement 4),[3] over a longer time period than is usually available in post acute rehabilitation units. This can achieve significant functional improvement to the point of discharge from the nursing home into the community. Even though such a programme can achieve a substantial reduction in care costs in the long term, it can be difficult to obtain funding support as these patients are often viewed as ineligible for NHS Continuing Health Care support. Their need for rehabilitation is cited as a barrier to CHC eligibility, as it infers that their condition has not stabilised, but often there are no other available sources of funding.

Institutional Definitions

1.8 Patients with a profound or complex disability can be discharged from hospital to:

- Private rehabilitation units - These are characterised by an active rehabilitation pathway and a short stay, with planning for discharge from the outset[4]
- Standard nursing homes - These predominantly cater for the elderly, and patients with a short life expectancy and dementia
- Specialist nursing homes - These have younger residents with longer lengths of stay and higher staffing levels, more complex management protocols and more specialist equipment than in standard nursing homes.

1.9 All such units are regulated by the Care Quality Commission (CQC). The CQC focuses on ensuring that there is acceptable general care of residents and cannot address specifically the complex medical and rehabilitation needs of patients with complex neurological disabilities. In this situation commissioners have the responsibility, on behalf of vulnerable patients and their families, to identify specialist units that can meet their needs and make a choice on quality and not just on cost. Specialist Nursing Homes often cost in excess of £950 per week; well above the usual funding envelope of social care and health departments.

Process Definitions

1.10 Specialist care of these patients is described as both rehabilitation and support, and can be divided into:

- *Complex Disability Management* - This has the aim of both preventing complications and enhancing participation and autonomy despite the restrictions of severe activity limitation. Such patients usually require:
  - a postural management programme
  - a management plan for cognitive, communication and behavioural impairments
  - maintenance physical therapy
  - provision of assistive technology and equipment
  - enteral nutrition and sometimes assisted ventilation and tracheostomy care.

- *Slow Stream Rehabilitation* - This refers to the achievement of rehabilitation goals amongst a subgroup of patients who have the potential to achieve significant functional improvement over a period of six months or more. Such longer term rehabilitation requires regular, but less frequent, one-to-one therapy contact, and relies extensively upon the facilitation of skill acquisition and functional improvement by care and rehabilitation assistant staff. These staff members gain personal expertise in the management

of individual patients and receive advice from qualified therapists on recommended rehabilitation approaches. The intensity of such a programme increases from:

- rehabilitation predominantly provided by care staff with infrequent but regular therapy review
- rehabilitation provided by trained rehabilitation assistants or technicians supervised by therapists
- hands on treatments by therapist enhanced by care staff using specified approaches at other times.

- *Neuro-palliative Rehabilitation* - This refers to the preservation of autonomy and relief of distress of patients with a complex disability, and family members, particularly when close to death. It is work at the interface between Rehabilitation and Palliative Medicine.[5,6] As the disease progresses there is increased reliance on skilled nursing and medical management in liaison with Palliative Care teams. Many professionals may become involved and their work needs to be carefully coordinated. Patient autonomy must be preserved as much as possible in the face of worsening cognitive and communication difficulties through the use of Advance Care Planning.

Aim of This Document

1.11 This guideline has been prepared by the British Society of Rehabilitation Medicine (BSRM) to describe the quality framework that SNHs should aspire to when managing patients with complex and profound disability. It introduces a method of defining and classifying SNHs through measures of case complexity, which can then be correlated with indicative tariffs. It includes a list of standards that commissioners can use to make a choice between units, and with which SNHs can audit the quality of their work. It is relevant to adults with either primarily physical or primarily cognitive problems consequent to neurological injury or disease, and complements a recent review of NHS provision for older people in care homes.[7] This guidance should be of particular interest to:

- Case Managers and health and social care commissioners
- Managers and clinical leads of SNHs
- Rehabilitation Medicine and other specialty consultants
- General Practitioners working in SNHs.

1.12 Although addressing practice in England and Wales, it will offer principles applicable to the whole of the UK.

2 Clinical Evidence and Methodology

Literature Review

2.1 General guidance on the overall care of patients in care homes has been published by expert bodies and summarised by the Care Quality Commission as:

- you can expect to be involved and told what is happening at every stage of your care
- you can expect care, treatment and support that meets your needs
- you can expect to be safe
- you can expect to be cared for by qualified staff
- you can expect your care provider to constantly check the quality of its services.

2.2 Clinical studies were sought within English language publications from 2000–2010. Principal references are both listed and evaluated at the end of this document. The evaluation followed the NSF typology[8] and describes the design, quality and applicability of each study. There are few studies that are directly applicable to the provision of care in this sector but the key findings are summarised here.

Rehabilitation Programmes

2.3 Patients with multiple sclerosis deteriorated rapidly in non-specialist care homes.[9] After admission from the community the frequency of infection and pressure ulcers was reduced but there was a rapid loss of functional ability and reduced access to therapy attention. There was a marked deterioration in mental health with loss of confidence in, and desire for, returning to the community with very little use made of psychological therapies.

2.4 A slow stream rehabilitation programme achieved improvement in cognitive functioning over 18 months, and motor functioning over 36 months, in patients with complex and profound disability who were not considered eligible for, or had not improved with, standard post-acute rehabilitation[10]. Similar improvement over a long period has also been described in patients with primarily cognitive or behavioural problems.[11,12] The introduction of 'reactivation facilities' in The Netherlands in 2001 increased the probability of discharge from nursing homes back into the community and this has been documented amongst patients with severe subarachnoid haemorrhage. When deaths are censored such patients had about a 50% chance of community discharge, usually within the first two years.[13]

2.5 Elderly patients who are provided with rehabilitation in nursing homes have a lower fatality rate and an increased likelihood of community discharge.[14]

Equipment Provision

2.6 Spinal injury patients described wide ranging benefits from regular standing.[15,16] Exercise programmes with partial body weight support can increase muscle mass and strength.[17,18]

2.7 Electronic assistive technology can benefit both patients and care staff.[19]

2.8 Gel or foam skin protection cushions can reduce peak pressures over bony prominences and are effective at preventing ischial pressure sores in the care home population.[20] Uncontrolled studies have indicated that customised adjustment to care home residents' wheelchairs can increase mobility, reach and social components of quality of life.[21]

Patient Safety and the Efficient use of Resources

2.9 The hospital admission of care home residents with serious infection is delayed if medical staff are on the unit infrequently or if they are communicating with unfamiliar staff.[22]

2.10 Hospital transfer of older residents with infection is associated with an increased risk of pressure ulcers and death.[23] Hospital transfer is also associated with an increased risk of medication errors and the stopping of important long term treatments.[24]

2.11 Ceiling hoists reduce the risk of injury to caregivers.[25-28]

2.12 Several of these studies are not applicable to current SNH practice in the UK and do not offer specific guidance on the commissioning of care or practice standards that should be pursued in this sector. Some primary research was therefore undertaken to inform these guidelines.

Primary Research

2.13 A Regional Rehabilitation Unit in North West London developed a network of two SNHs to which selected patients could be transferred on completion of their post-acute rehabilitation.[29] The larger of these has 112 beds and can manage complex patients with tracheostomy or requiring ventilation. This development has become the focus of service development and research in this sector.

- In 2005 there were 14 ambulance calls a month to the SNH. The local NHS hospital and host Primary Care Trust were concerned at the large number of nurse heralded 999 ambulance admissions to critical care. The local GP practice was also concerned at the increased volume of work and the lack of skills in primary care to manage these more complex cases. A newly recruited GP received relevant training and started to provide two ward rounds a day, telephone advice and emergency visits. The number of unscheduled hospital visits dropped to an average of 1.5 a month for the period 2005-2011.
- The SNH had regular input from a community pharmacist. This reduced drug expenditure with £6000 being saved by the use of a different preparation of Glycopyrronium alone.
- A cohort of 48 admissions to the SNH was followed for up to 13 years with intermittent measurement of the Northwick Park Dependency Score (NPDS).[30] Twenty one (44%) received complex disability management and 13 of these patients subsequently died. Twenty seven (56%) patients received slow stream rehabilitation. Seventeen (63%) of these patients were discharged between one month and nine years with 11 returning to the community after a median of eight months. Their median NPDS reduced from a median of 37 on admission to 22 on discharge home.

2.14 A postal questionnaire was circulated to all UK consultant members of the BSRM.[31] Forty seven (38%) of the 124 respondents attended SNHs with 15 visiting a Nursing Home at least every month. They provided a range of rehabilitation and medical interventions including spasticity treatments, bowel and bladder care, and assessments of pain, mental capacity, posture, seating, assistive technology and behaviour. They expressed concern about communication within some units, the level of neurological expertise and variable GP involvement. There was widespread support for SNH practice being included in the specialist training curriculum for Rehabilitation Medicine.

2.15 The standards described in this document were disseminated in draft form to a convenience sample of 30 SNHs.[32] The standards for medical support were met by 83% and aspired to by a further 8%. The standards for nurse competencies were met by 73% and aspired to by 13% and standards for equipment were largely met by 83%. The standards were viewed therefore as being largely appropriate for this sector, but it was noted that almost half of the units did not aspire to competence in the assessment of patients in low awareness states and a quarter did not always have a nurse available with competence in the management of tracheostomy and respiratory care. There appeared to be some subspecialisation within the SNH sector and this was reflected in the final version of the standards.

2.16 The Rehabilitation Complexity Scale[33] was adapted, through discussion with experienced staff and within the Guideline Development Group, to reflect the needs of patients in this sector. This new scale, the RCS-SNH, is described in appendix 1. It is quick to complete and is validated against another measure of complexity (the NPDS) in section 3.

A 54 year old man presented with tetraplegia and severely impaired communication after a brain stem infarct. At five months, he was transferred to a Specialist Nursing Home with a tracheostomy and able to sit for only two hours. He communicated with an alphabet board. Seven years later he is still in nursing home care but less dependent. He speaks without a tracheostomy, can operate an electric wheelchair and laptop and walks with assistance.

A 30 year old lady presented with encephalitis, possibly due to SLE. Twelve months later she was admitted to a Specialist Nursing Home in a low-awareness state and reliant on PEG feeding. Following plasma exchange this was eventually removed and she was discharged home three years later, able to transfer with a sliding board and with normal speech.

3 Challenging Issues in Specialist Nursing Home Care

Commissioning Slow Stream Rehabilitation

3.1 Specialist post-acute rehabilitation is usually completed by six months. Rehabilitation beyond that time should be described as slower stream but is usually seen to lie outside the arrangements for NHS CHC in England and Wales. There is a need for a defined funding stream to support it. Exceptional treatment panels may be used but their expertise is more within therapeutics and equipment provision. Funding responsibility may need to be shared with the local authority and a multiagency panel may need to be formed if protracted negotiations are to be avoided. It is recommended that the needs of such patients are taken on by specialist commissioners in liaison with a consultant in Rehabilitation Medicine and other clinicians involved with specialist rehabilitation. Many programmes are then kept under review by a specialist practitioner or case manager.

3.2 The survey described in section 2 suggested a classification of patients into those whose needs were primarily physical (PhysD) and those whose needs were primarily around cognitive and behavioural management (CB). The needs of these patients can be described with reference to their complexity level as in Table 1. Highly complex patients would require regular supervision by specialists, complex patients would require regular access to specialists and standard patients would not usually need specialist care at all.

Table 2
Classification of patients requiring SNH care and services

Physical disability (PhysD) Primary needs are for physical care	Cognitive/behavioural (CB) Primary needs are for CB management
PhysD Category A: Highly Complex Severe-profound PhysD with one or more of ● tracheostomy/ventilation ● very complex spasticity ≥ two to handle ● very challenging behaviours ● Low Awareness State requiring specialist assessment (SMART/WHIM) ● specialist medical issues requiring active treatment (eg epilepsy, spasticity) ● complex therapy needs requiring both a coordinated nursing and therapy team approach and hands on sessions ● requires highly customised equipment	**CB Category A: High Risk** Severe-profound CB requiring one or more of ● very challenging physically aggressive behaviour ● 1:1 continuous supervision (trained carer) ● treatment under DoL or MHA section ● neuropsychiatric issues requiring active treatment ● may have associated Phys D ● complex therapy needs requiring coordinated team approach
PhysD Category B: Complex Moderate-severe PhysD with neurological needs eg ● complex spasticity requiring 24 hr postural management ● PEG feeding ● cognitive/communication needs ● Low Awareness State in long term care ● medical issues requiring review/monitoring by a consultant in RM ● requires daily therapeutic input from rehabilitation assistants or care staff overseen by professional therapist(s)	**CB Category B: Moderate Risk** Moderate-severe CB (walking wounded) ● moderate-severe challenging behaviours ● requires close monitoring or part time 1:1 supervision (non-skilled eg care assistant) ● neuropsychiatric issues requiring review/monitoring ● requires closely structured programme overseen by professional therapists (eg psychology/SLT etc)
PhysD category C: Standard PhysD without complex needs ● requiring standard nursing care – not necessarily with neurological experience	**CB Category B: Standard** CB without complex needs ● able to maintain own safety with standard precautions ● any behavioural issues are easily contained in a structured environment

DoL	Deprivation of Liberty Safeguard within the Mental Capacity Act
MHA	Mental Health Act
RM	Rehabilitation Medicine
SLT	Speech & Language Therapist
SMART	Sensory Modality Assessment and Rehabilitation Technique
WHIM	Wessex Head Injury Matrix

3.3 Nursing homes can thus be divided by the complexity of patients that they manage:

Level 1 Highly Specialist Nursing Home
with onsite multidisciplinary therapy and medical/neuropsychiatric support
able to manage patients with category A PhysD or CB needs

Level 2 Specialist Nursing Home
with at least visiting multidisciplinary therapy and medical/neuropsychiatric support
able to manage patients with category B PhysD or CB needs

Level 3 Non-specialist Nursing Home
able to manage patients with category C PhysD or CB needs.

3.4 Different levels of clinical need correlate with scores on the NPDS and RCS-SNH. These scales can be used as useful measure of case mix (Table 3).

Table 3
Categories of Specialist Nursing Home Care defined by NPDS and RCS-SNH

Grade	Descriptor	Approx cost range
Basic	Standard room with up to four hours basic care per day ● under supervision of nurses trained in management of patients with neurological disability ● SNH caters specifically for needs of younger adults ● patients have access to programme of group therapy/activities etc ● basic PhysD maintenance programme is undertaken by carers ● occasional review by GP when requested by care staff For patients largely independent and low risk **Typical NPDS: 0-10** **Typical RCS-SNH: ≤5** (R0-1) C1 N0-2 T0-1 M0 E0-1	£950-1050 per week
Intermediate	Standard room with extra care and/or low level therapy ● up to an extra four hours care (eg from a 2nd carer) ● care mainly by care assistants with specialist nursing supervision ● low level therapy programme overseen by therapy staff (eg review every one-two weeks) ● basic medical management/monitoring by GP only For patients with moderate PhysD and low risk **Typical NPDS: 11-20** **Typical RCS-SNH: 6-10** (R0-1) C1-2 N1-2 T 2-4 M0-1 E0-1	£1250-1500 per week
High	Specially equipped room with complex care programme involving nursing and professional therapy staff inputs ● >eight hours care per day with hands on nursing input ● coordinated therapy/maintenance programme with hands on treatment by trained therapists ● regular medical review with specialist support/advice if needed For patients with severe PhysD and low-moderate risk **Typical NPDS: 21-40** **Typical RCS-SNH: 11-14** (R1-2) C2-3 N2-3 T 4-5 M1-2 E2	£1600-2200 per week
Very high	Specially equipped room with highly complex MD care programme ● care as needed – usually by two-three carers, or 1:1 supervision ● care delivered by skilled carers/trained specialist nurses ● highly specialist equipment/facilities ● intensive MD therapy/maintenance programme ● active specialist medical care For patients with very severe PhysD or high risk eg on ventilator or **Typical NPDS: >40** **Typical RCS-SNH: ≥15** (R2-3) C2-3 N3 T 5-6 M2-3 E3	£2200-4500 per week

3.5 Within Level 1 and 2 SNHs, funding categories can therefore be defined using the RCS-SNH as a measure of clinical and rehabilitation need and the NPDS as a measure of nurse dependency. These categories attracted a corresponding increase in weekly tariff in two of the networked SNHs described in section 2. These tariffs are for illustration only, and will clearly vary over time and between areas, but demonstrate a close correlation of variable cost with these two measures of case mix. A single institution may include a number of services at different levels.

A 70 year old lady presented with HSV encephalitis. At three months she was transferred to a Specialist Nursing Home in a low awareness state and reliant on PEG feeding. Eighteen months later, she was returned to the Regional Rehabilitation Unit for a programme of treatment that included lengthening of achilles tendons. Two years later, she was discharged to a residential home close to where she lived, walking with one stick and eating a normal diet but still intermittently confused.

Commissioning Complex Disability Management

3.6 The needs of such patients are not met within the usual funding envelope for nursing home care. The majority are assessed in England and Wales as eligible for continuing NHS care but this is not always the case (see vignette) and funding may need to be sought from multiple sources. It is inappropriate to seek necessary therapy support from statutory NHS services where this involves attendance at hospital outpatient services or in-reach from a community rehabilitation team that cannot maintain long term support. It is often more appropriate to select a SNH that already employs therapists and negotiate funding responsibility whereby for instance the local authority is responsible for 'hotel costs' but not for the specialist nursing and therapy input. In order to avoid protracted disputes it may be valuable to have access to a multiagency panel. The need for close cooperation between health and social services was emphasised within the NSF for Long-term Conditions and was also the subject of a recent report on neurological services.[34]

3.7 The standards outlined in this document should inform the choice of unit for such patients, and be considered alongside financial and geographic priorities. The chosen unit should have current experience and a track record in successfully managing such patients. If it is planned that a local rehabilitation team should in-reach into the home they should be consulted in advance. Agreement should also be sought from the GP taking on responsibility and from the referring specialist clinicians.

A 47 year old man with severe Parkinson's disease was admitted to a Specialist Nursing Home anarthric, malnourished with inflamed pressure areas. After a few months and following insertion of a PEG and a postural management programme, he was independent in an electric wheelchair. Consequent to this he lost eligibility for NHS Continuing Healthcare and was discharged to a non-specialist home. One year later he had to be readmitted with pressure sores, malnutrition and loss of his previous seating ability.

A 57 year old man with Spina Bifida who was ventilator dependent, was admitted with self-neglect and multiple sores that took seven months to heal. He learnt to trust staff and eventually was successfully seated. He wished to return home. He was discharged with 24 hour care but had to be admitted to a local hospital within one week because of immobility and infection.

3.8 Commissioners can use the RCS-SNH and NPDS to determine the need for more complex provision and the corresponding higher tariff.

Staff Recruitment and Retention

3.9 Skilled nursing and therapy staff are scarce and will opt, when available, for NHS contracts. Overseas recruitment can be successful, particularly from countries with established training courses. If their language skills meet IELTS requirements, and they fulfil skilled immigration criteria, staff can be taken on for a 3–6 month Adaption Course which can often be provided by a local university. After passing this they can then apply for Nursing and Midwifery Council (NMC) registration. Staff retention depends upon the quality of clinical and managerial leadership and is helped by providing opportunities for career progression and further training.

3.10 Therapy staff may be employed directly by the SNH or seconded from NHS services. NHS staff are likely to have a broader knowledge of local services which would make a final discharge into the community easier, and will have the benefit of continuing educational opportunities and the collegiate support of their peers. They may not, however, be sufficiently available to the SNH to participate in an effective multidisciplinary team or develop working relationships with nursing staff, and many SNHs elect to employ their own physiotherapists and occupational therapists but offer sessions to visiting Rehabilitation Medicine Consultants, speech and language therapists and clinical psychologists.

Complex Seating

3.11 There is frequent need of customised wheelchairs that offer a high level of postural support. The level of postural support can often be reduced by a rehabilitation programme and seating would need to change. Frequently patients are issued initially with multi-adjustable or modular seating and then moved to a customised, contoured seat as their condition stabilises. The provision of good supportive seating can have a marked effect on the function and prognosis of patients.[35] Such chairs are expensive and could be difficult for a district wheelchair service to fund. It is more appropriate for the cost to come from a specialist rehabilitation or CHC budget which should include replacement and maintenance. It is recommended that this need is identified prior to transfer and included in estimated costs.

3.12 Very severely impaired patients, including those in vegetative or minimally responsive states, may be unable to go out of the unit nor operate a powered chair, thus not fulfil the eligibility requirements for local NHS provision. They may instead be issued with static chairs and commissioners may view provision of these to be the nursing home's responsibility. Patients may then suffer:

- the lack of a tilt in space facility and inadequate postural support which may make oral nutrition more hazardous,[36] reduce attentiveness and put them at risk of contractures and pressure sores
- loss of opportunity to go out of their rooms or to the garden which can lead to sensory deprivation and make it more difficult for the family to visit
- difficulties accessing bathing facilities or with the use of hoists.

3.13 It is recommended that all seating for this patient group is on a wheeled base and the majority with complex or highly complex physical disability are better seated in a wheelchair with a tilt in space facility and a custom contoured or modular seat. Wheelchair services can provide modular seating that can be fixed to framed static chairs with castors which may be an option for patients who do not meet the mobility requirements of NHS services. Commissioners must ensure that these patients' seating needs are adequately assessed and reviewed by suitably experienced clinicians. A few patients have such a severe movement disorder that they tip wheeled chairs over and must be sat in a wide-based (eg 'Huntington's) static chair.

Joanna's response to appropriate seating was quite remarkable. There was a marked reduction in the tone in all her limbs and a restoration of normal sitting postures. What was perhaps more unexpected, and somewhat overwhelming to those present, was the dramatic change in Joanna's overall presentation. Her facial expression changed, it seemed to relax and appear more engaged, her breathing pattern settled and her response to external stimuli appeared to increase. The effect overall was of changing Joanna from being a minimally responsive patient in a bed to being Joanna, sitting in a chair with whom it was easy to establish purposeful interaction. I could not help but think what a huge change this seating system would make to Joanna and her family.

Assistive Technology

3.14 Nursing homes are required to respect patient choice and offer an environment that is as close to home as possible. Younger residents may be living there for a long time and protocols and restrictions drawn up for the majority, very elderly, nursing home population, may not be appropriate for this patient group. There may well be need for more socialisation opportunities, such as going out of the unit with an assistant, or more access to computers and electronic assistive technology. Qualitative research on neurological patients in SNHs and rehabilitation units has emphasised the importance of access to the internet and to remain in email contact with their social circle.[37] Environmental control equipment can make a substantial difference to the dependence and frustration experienced by many residents.[19] Such equipment needs to be made available to patients who might benefit. If it is not available within the SNH it should be provided by either the SNH itself or NHS services. If the SNH does provide some electronic

assistive technology then the customisation of such equipment for the particular needs of a patient, or the provision of specialist assistive technology reflecting unusual individual patient requirements, is the responsibility of the local NHS assistive technology service in liaison with equipment manufacturers. Nursing home residents are entitled to general NHS services which includes the provision of electronic assistive technology and communication aids.

A 50 year old lady who is tetraplegic after brain injury controls a keyboard emulater with her head using SmartNav technology. This allows her to keep a narrative blog and maintain email contact with her husband and family.

Patient Autonomy

3.15 Offering residents some autonomy and control with regard to weekly and daily schedules, and giving opportunities to choose between alternatives, reduces the impact of instutionalisation and enhances their quality of life.[38] The autonomy exercised by residents who lack capacity should be carefully monitored, and facilitated according to the principles of the Mental Capacity Act.[39]

A 71 year old patient with diabetes was transferred to a Specialist Nursing Home following spinal infarction, tetraplegia and pressure sores. He was advised to remain as a resident but wished to return home by Christmas. He was assessed as retaining capacity for this decision. Care was provided at home but at two months he developed pneumonia and died in hospital.

3.16 A key principle in retaining autonomy is the practice of Advance Care Planning (ACP) as described in the Gold Standards Framework.[40] This is difficult in the context of complex neurological disability as many patients do not have a progressive disorder and may have a long potential life expectancy. Moreover the process can be viewed as a form of defensive practice by institutions anxious about their liability on admitting vulnerable patients. ACP can only be undertaken when therapeutic relationships have had a chance to develop and not immediately after transfer to a SNH. However the predictable death of a long term resident in hospital, away from their familiar staff and environment, should be considered as an adverse event, and residents need to be given the opportunity to make advance preferences, draw up Advance Directives and/or appoint a Lasting Power of Attorney whilst they are well and with staff who have experience of communicating with them. This should, whenever possible, include relatives, who need to have input into medical decision making on behalf of their loved ones.[37] Any ACP documents should be reviewed by staff and patients at least every six months and should accompany patients on admission to hospital.

Access to NHS Specialists

3.17 There is concern that SNHs operate in isolation from mainstream NHS services with limited access to secondary care specialists. The British Geriatrics Society has made specific recommendation for increased involvement of Consultants in Elderly Care.[7] The BSRM found, in a survey of 124 members, that only 47 (38%) respondents provided input into nursing home residents with only 15 visiting regularly every month. It is hoped that application of the standards outlined in this document will promote more consistent consultant involvement with this patient group.

3.18 The continued management of such patients may involve multiple medical specialties. Correspondence needs to be available to senior staff and it is recommended that letters and laboratory results are copied to senior nursing staff and incorporated in a medical record held within the SNH. Residents should be accompanied to consultations by informed staff and it is very helpful if the SNH prepares a written record of current medication and current clinical issues. An example is included in appendix 2.

The Humanisation of Institutional Care

3.19 Qualitative research on neurological patients and their relatives in SNHs[37,38] emphasises the importance of staff continuity and the development of an emotional bond between staff and residents, and between the residents themselves, leading to a sense of community and home. In order to achieve this both care and therapy staff should be well trained in the skills needed to communicate effectively with

patients who have severe impairments. Affectionate touch is also an important way of retaining a sense of being human and connected, particularly for those with severe neurological impairments, as is the chance to be involved as a group in creative activities, mealtimes and trips out of the unit.

3.20 Younger patients with progressive disease may find the transition into institutional care particularly difficult. Successful adaption requires both a change in attitude on the part of the resident, and a supportive social environment.[41] The adaption process has features of a 'response shift' in that it requires a significant change in the resident's internal standards, values and conceptualisation of quality of life, which needs to be supported by peer relationships with others of similar age and ability. The placing of a younger person in a unit where these opportunities are not available or supported puts them at risk of not establishing the social ties that are necessary for a good quality of life and should be avoided.[38]

3.21 Pets are an established feature of elderly residential care as they can play an important role in humanising an institution. They have also been used in specialist care and rehabilitation. An empathic and well trained dog can not only bring joy to a resident coping with severe impairments, but also encourage excursions outside the unit and facilitate conversation with both staff and other residents.

4 Recommended Standards

4.1 The following standards are derived from consensus discussion between clinicians experienced in SNH care and rehabilitation/support. Draft standards were circulated for comment to 30 units identified by members of the BSRM who are active in this area.[31] Standards that are largely unmet, or not aspired to, were removed or replaced. The resulting proposed standards were approved by representatives of families, regulatory authorities, commissioners, clinicians, social services and providers.

4.2 The standards are kept as general as possible. No specific outcome measures are recommended, apart from the consistent recording of goal achievement, but Goal Attainment Scaling may be an appropriate way of reporting and standardising this. Reference is made to the classification of patient needs and the different types of SNH care described in section 3, with more demanding standards being applied to units that care for more complex patients. Individual standards are described according to whether they are applicable to Level 2 (Specialist) as well as Level 1 (Highly Specialist) units, and whether they are applicable to Cognitive Behavioural (CB) as well as Physical Disability (PhysD) units.

Standards

	Nursing care	PhysD	CB
S1	All qualified nursing staff have specialist knowledge/experience of managing Long Term Neurological Conditions (LTNC) including:		
	S1.1 tracheostomy and respiratory care	1	-
	S1.2 management of challenging behaviours	-	1
	S1.3 24-hour postural management	1+2	-
	S1.4 pain and spasticity management	1+2	-
	S1.5 oral and enteral feeding	1+2	-
	S1.6 management of neurogenic bladder and bowel	1+2	-
	S1.7 tracheostomy and respiratory care	1+2	
	S1.8 communication with residents with cognitive/communicative impairments	1+2	1+2
	S1.9 management of residents who lack mental capacity	1+2	1+2
	S1.10 support for distressed/challenging families	1+2	1+2
S2	There is at least one qualified nurse on each shift with specialist knowledge/experience and clinical competency in management of tracheostomy and respiratory care	1	-
S3	All care assistants have specific training in the management of residents with LTNC to a level of competency appropriate for their role	1+2	1+2
	Medical care		
S4	A GP with special interest in the management of complex neurological disability provides regular support for residents within the Home (including regular rounds)	1+2	1+2
S5	There is a defined system for access to specialist advice for management of specific diseases (eg the assessment and management of mood disorders, the optimal control of seizures, drug treatment of Parkinson's disease, etc)	1+2	1+2
S6	For residents with highly complex disability arising from their neurological condition, there is regular supervision from a consultant specialist in neurological rehabilitation medicine/spinal injuries for physical disability management or from a consultant specialist in psychiatry or neuropsychiatry for cognitive and behavioural management	1	1
S7	Advice from the relevant medical specialties should be available as required, including Rehabilitation Medicine, Palliative Care, Psychiatry, Elderly Care and Neurology	1+2	1+2
S8	Appropriate dedicated space should be available for confidential medical consultation	1+2	1+2
	Access to facilities and therapies		
S9	Specialist Nursing Homes (SNHs) should have the appropriate facilities and equipment to manage residents with complex neurological disability **Minimum requirements include:**		
	S9.1 safety equipment including low level beds and alarms	1+2	1+2
	S9.2 adjustable beds	1+2	-
	S9.3 disability-adapted resident rooms	1+2	-
	S9.4 suctioning equipment	1+2	-
	S9.5 a dedicated gym area	1+2	-
	S9.6 standing frames/tilt table	1+2	-
	S9.7 appropriate hoisting equipment, including ceiling tracked hoists where appropriate and feasible	1+2	-
	S9.8 bathing and toileting equipment	1+2	-

S10	The majority of therapy is delivered by care staff. However, there should be an initial assessment and review by an appropriately skilled multidisciplinary team, support from therapy professionals and/or clinical psychologists with experience in the management of neurological disability to advise on the appropriate therapy programme and to train care staff in its delivery	1+2	1+2
S11	All residents with complex physical disability should have an appropriate maintenance therapy (MT) programme in place as part of their routine care *(For management of pain and spasticity, and to prevent contractures and deformity)*	1+2	-
S12	MT programmes for complex physical disability should include: S12.1 a suitable postural management programme (eg a written plan for sitting out in a suitable chair, upper limb support etc) S12.2 regular standing/tilt tabling at least twice a week S12.3 splinting and stretching routines – including expert provision and adjustment of orthoses	 1+2 1+2 1+2	 - - -
S13	MT programmes should be overseen by a qualified physiotherapist or OT with specialist experience in neurological disease, who is responsible for S13.1 training/advising the care staff in implementation of MT S13.2 monitoring its effectiveness	 1+2 1+2	 - -
S14	All residents with cognitive/communicative impairments should have at least a basic programme in place to optimise communication and cognitive interaction	1+2	1+2
S15	Basic cognitive/communicative programmes should include: S15.1 a written communication plan, with simple aids as appropriate (eg alphabet chart, picture book) S15.2 simple cognitive aids as appropriate (eg orientation board)	 1+2 1+2	 1+2 1+2
S16	Residents with more complex cognitive/communicative/behavioural disability should have an assessment by a speech and language therapist or psychologist to draw up a detailed care plan and to train care staff in its implementation	1+2	1+2
S17	There should be opportunity to generalise skills to more normal environments outside the nursing home, eg day leave at home	1+2	1+2
S18	S18.1 There should be access to appropriate seating which provides suitable postural support and pressure relief S18.2 Seating systems should be reviewed regularly (at least once per year) by an appropriately skilled professional and provision adjusted to changing needs	1+2 1+2	- -
S19	Commissioning arrangements should ensure the timely provision and replacement of necessary equipment	1+2	1+2
	Rehabilitation programme, goals and outcomes		
S20	Active/slow stream rehabilitation programmes should be goal–orientated: S20.1 each resident should have a timed set of outcome goals with the resident and/or their family involved as far as possible in goal setting S20.2 goal achievement should be reviewed/reported at appropriate intervals determined by the length of the programme S20.3 There should be an appropriate set of outcome measures	 1+2 1+2 1+2	 1+2 1+2 1+2
S21	Active/slow stream rehabilitation programmes should be multi-disciplinary and coordinated: S21.1 The multidisciplinary team should meet regularly to ensure coordinated care S21.2 Residents' records should be multidisciplinary	 1+2 1+2	 1+2 1+2
S22	A set of goals or actions should also be drawn up for patients receiving complex disability management. These could be process or maintenance goals/actions but reviewed at a frequency appropriate to the patient's management and combined with appropriate outcome measures	1+2	1+2
	Assessment, co-ordinated care, communication and discharge		
S23	All referrals should be assessed by a senior team member (nursing, therapy and/or medical) within two weeks from the time of referral	1+2	1+2
S24	Following assessment, a written summary should be provided within one week which includes S24.1 a summary of the case and individual's care, medical and rehabilitation needs S24.2 proposed management and intervention with estimation of the resources required S24.3 provision of descriptive information of the service	 1+2 1+2 1+2	 1+2 1+2 1+2

S25	Care should be provided by appropriately skilled nursing staff with support from a multidisciplinary team and access to General Practitioners with a special interest in managing residents with long term neurological conditions S25.1 residents who are admitted to hospital should be sent with an up to date clinical summary S25.2 residents should be accompanied to clinical appointments by senior staff who are familiar with the resident's care	 1+2 1+2	 1+2 1+2
S26	The multidisciplinary team should meet with the resident and family for goal negotiation, rehabilitation planning and an update on clinical progress S26.1 within 4 to 6 weeks from admission S26.2 every 3 to 6 months thereafter S26.3 incorporating key workers who can ensure clear lines of communication with the resident, family, funders, advocates, case managers, etc	 1+2 1+2 1+2	 1+2 1+2 1+2
S27	There should be timely planning with resident, family and all relevant agencies including community health care, social services and housing incorporating home visits when necessary to ensure appropriate environmental modifications	1+2	1+2
	Family and staff support		
S28	Staff should be aware of the high levels of distress experienced by families of residents with LTNC. Systems should be in place for supporting families including S28.1 access to appropriate and timely information S28.2 regular meetings with staff to offer support	 1+2 1+2	 1+2 1+2
S29	Caring for residents with complex disability can be a highly challenging area of care and facilities should be available for staff support eg S29.1 peer support through reflective practice S29.2 workplace chaplains S29.3 counselling and other external support	 1+2 1+2 1+2	 1+2 1+2 1+2
	Legal issues		
S30	Specialist Nursing Home staff should have access to legal advice and a basic understanding of the relevant medico-legal issues including: S30.1 mental capacity assessment S30.2 welfare deputy and best interests decisions S30.3 lasting power of attorney/court of protection S30.4 advance care planning S30.5 safeguarding of vulnerable adults	 1+2 1+2 1+2 1+2 1+2	 1+2 1+2 1+2 1+2 1+2
S31	The capacity of residents should be assessed and facilitated as per the Mental Capacity Act. A personal assessment should be made of patients who lack capacity for critical decisions covering values, preferences, relationships, spiritual and religious welfare and financial interests, with a view to holding a best interests meeting with family and staff within the first four weeks	1+2	1+2
	Advance care planning and end of life care		
S32	S32.1 Senior staff should discuss future care with the resident and family and prepare, when appropriate, advanced care planning documents within six weeks of admission which should be reviewed at least every six months or sooner as necessary S32.2 There should be easily accessible documentation, where relevant, of mental capacity assessments, lasting power of attorney arrangements, Court of Protection decisions, safeguarding of vulnerable adult restrictions, best interest meetings, advance care plans, and resuscitation status etc	1+2 1+2	1+2 1+2
S33	Support should be provided for advance care planning where appropriate	1+2	1+2

Appendix 1

The Rehabilitation Complexity Scale for Specialist Nursing Homes (RCS-SNH)

PATIENT IDENTIFICATION

Name: **Hospital No:** **Date of score:…../…../…….**

For each subscale, circle highest level applicable

BASIC CARE AND SUPPORT NEEDS or **RISK for safety** **(Score highest of Care OR Risk)**

Describes the approximate level of intervention required for basic self-care or safety monitoring (risk) in walking wounded pts.

C 0	Largely **independent** in basic care activities	**R 0**	**No risk –** maintains own safety, summons help if needed
C 1	Requires **help from 1 person** for most basic care needs	**R 1**	**Low risk – standard precautions** for safety monitoring
C 2	Requires **help from 2 people** for most basic care needs	**R 2**	**Medium risk – additional safety measures** eg alarms, tagging, or extra supervision some of the time
C 3	Requires **help from >2 people** for basic care needs **OR** Requires constant **1:1 monitoring**	**R 3**	**High risk –** risk of wandering /absconding Requires continuous **1:1 supervision**

SKILLED NURSING NEEDS

Describes the level of intervention required from qualified or highly skilled nursing home staff

N 0	No needs for qualified skilled nursing – needs can be met by trained care staff only
N 1	Requires intervention from a **qualified nurse** (eg for monitoring, medication, dressings etc)
N 2	Requires intervention from **skilled nursing staff trained in complex disability management**
N 3	Requires **highly specialist nursing care** (eg for ventilator, behavioural management, end of life support etc)

THERAPY NEEDS

Describes the approximate level of input that is required from therapy disciplines

Disciplines: State **number of different therapy disciplines** required to be actively involved in treatment

TD 0	**0**	**Tick therapy disciplines involved:**		
TD 1	**1** disciplines only	☐ Physio	☐ Psychology/Counselling	☐ Orthotics
TD 2	**2-3** disciplines	☐ O/T	☐ Chiropody	☐ Prosthetics
TD 3	**≥4** disciplines	☐ SLT	☐ Music/Art therapy	☐ Rehab Engineer
		☐ Dietetics	☐ Aromatherapy	☐ Other:

Intensity: State **overall intensity of therapy intervention** required

TI 0	**No therapy intervention** required – any rehab needs met entirely by nursing/care staff or self-exercise programme
TI 1	Low level – **maintenance therapy** (eg programme provided by care staff with therapist review every 6-8 wks)
TI 2	Moderate – **active goal-orientated therapy programme** **(**delivered by care team, but with frequent therapist review eg every 1-2 weeks)
TI 3	High level – intensive **goal-orientated therapy programme** - primarily delivered by therapists.

MEDICAL NEEDS

Describes the approximate level of medical care environment required for medical/surgical management

M 0	**No active medical intervention** (Occasional review by GP when requested by care staff)
M 1	**Primary care monitoring / treatment –** delivered through routine ward rounds by GP/nursing home doctor (eg requiring regular review for active monitoring of anticoagulation, BP or seizure control etc)
M 2	**Specialist medical or neuropsychiatric care** (Requiring review, input or intervention from visiting specialist, in addition to GP monitoring)
M 3	**Acutely sick or potentially unstable medical condition - or intensive end-of-life support** (Requiring intensive medical intervention/review, ie on a daily basis or almost every day)

EQUIPMENT NEEDS

Describes the requirements for personal equipment or special facilities

E 0	**None**	**Basic equipment**	**Specialist**	**Highly specialist**
E 1	**Basic** equipment – off the shelf or shared equipment	☐ Standard wheelchair ☐ Standard walking aids ☐ Off the shelf orthotics ☐ Low tech pressure relief ☐ Shared equipment eg suction, manual standing frame Other:	☐ Special seating eg tilt-in-space with supports ☐ Bespoke orthotics ☐ High tech pressure relief ☐ Own suction etc ☐ Electric standing frame, tilt table etc ☐ FES /TNS machine	☐ Ventilator ☐ Highly customised seating or other equipment ☐ Bespoke sleep system ☐ ECU ☐ Communication aid Other:
E 2	**Specialist** equipment			
E 3	**Highly specialist customised personal** equipment			

Appendix 2

OUTPATIENTS ATTENDANCE FORM

Date : ……..

Name of Patient:……..

Address……..…

……..

N.H.S. Number: ……..…….. Date of Birth: ……..

Current GP: ……..……...

Clinical lead at the Nursing Home……..……

Diagnoses:

Please see a listing of current medication on the attached sheet

Any relevant advance directives or care plans Yes/No (*relevant documentation will be attached)*

Clinical Issues:

Recent changes in management:

Other relevant information:

Signature: …… Position:…..……

Consultants comments (treatments or changes in management): ……..

……

……

……

NB Could a copy of the GP letter be sent to the clinical lead listed above

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