Rehabilitation for chronic neurological disorders including acquired brain injury

Draft for consultation, April 2025

This guideline covers rehabilitation in all settings for children, young people and adults with a chronic neurological disorder, neurological impairment or disabling neurological symptoms resulting from acquired brain injury, spinal cord injury or peripheral nerve disorder, progressive neurological disease or functional neurological disorder.

It does not cover chronic neurological disorders covered in NICE's guidelines on dementia, cerebral palsy in adults, cerebral palsy in under 25s and stroke rehabilitation in adults. It also does not cover isolated peripheral nerve injuries.

For hospital and early community-based coordination of rehabilitation for people with traumatic brain injury (as part of multiple injuries) and traumatic injury to the spinal cord, and for specific rehabilitation interventions for people with spinal cord injury (who are not currently in a regional specialist spinal cord injury centre), see NICE's guideline on rehabilitation after traumatic injury. See also NICE's guideline on spinal injury: assessment and initial management.

For guidance on assessment and early management of head injury, see NICE's guideline on head injury. For guidance on managing brain tumours, including neurorehabilitation, see also brain tumours (primary) and brain metastases in over 16s.

For people with a progressive neurological disease see the following guidelines, which include additional recommendations about rehabilitation in the context of management and treatment that should be followed together with the recommendations in this guideline:

motor neurone disease: assessment and management

Parkinson's disease in adults

multiple sclerosis in adults: management.

See also NICE's guideline on intermediate care including reablement, which may be appropriate for some people with short-term rehabilitation needs.

Who is it for?

- Healthcare and social care practitioners
- Commissioning groups that provide or commission neurological rehabilitation services (including local authorities)
- Other providers of neurological rehabilitation services in the community, including third sector and private sector providers
- People with a chronic neurological disorder, their families and carers, and the public
- Practitioners working in related services, including employers, education, housing, leisure, job centres, welfare advice and legal
- Advocates for people with a chronic neurological disorder.

Although recommendations are not intended to apply in prisons or military hospitals, this guideline may be of interest to professionals working in these settings.

What does it include?

- the recommendations
- recommendations for research
- rationale and impact sections that explain why the committee made the recommendations and how they might affect practice
- the guideline context.

Information about how the guideline was developed is on the guideline's webpage. This includes the evidence reviews, the scope, details of the committee and any declarations of interest.

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People have the right to be involved in discussions and make informed decisions about their care, as described in NICE's information on making decisions about your care.

Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

Healthcare and social care practitioners should follow our general guidelines for people delivering care:

- Patient experience in adult NHS services
- Babies, children and young people's experience of healthcare
- Disabled children and young people up to 25 with severe complex needs
- Service user experience in adult mental health
- People's experience in adult social care services
- Shared decision making
- Medicines optimisation
- Multimorbidity
- Transition from children’s to adults’ services
- Transition between inpatient hospital settings and community or care home settings for adults with social care needs
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1.1 Service design

1.1.1 Ensure rehabilitation services and care pathways are designed and developed in partnership with the people who use them and the healthcare and social care practitioners who deliver them.

1.1.2 Use inclusive and proactive strategies to seek feedback from people with a chronic neurological disorder about their experiences of rehabilitation and use this feedback to inform service design.

1.1.3 Design rehabilitation services for people with a chronic neurological disorder that:

- address their rehabilitation needs, from when they first develop symptoms or impairments, or they are diagnosed
- have lifelong support and care in mind
- operate across all health and care settings, including hospital and community rehabilitation services, primary care and home care (including third sector and private sector providers)
- take into account the mix of specialist neurorehabilitation services and general rehabilitation services required.

1.1.4 Establish integrated, collaborative and flexible clinical pathways across hospital and community rehabilitation services to address people's needs throughout their life.

1.1.5 Agree who has overall designated responsibility for implementing clinical pathways for children, and, separately, for adults, taking into account local and national commissioning responsibilities.

For a short explanation of why the committee made these recommendations and how they might affect services, see the rationale and impact section on service design.

Full details of the evidence and the committee's discussion are in evidence review A: rehabilitation delivery.

1.2 Commissioning rehabilitation services and service specifications

1.2.1 Commission services to ensure that people with a chronic neurological disorder have access to a single point of contact, that is a key contact, key worker or complex case manager depending on their rehabilitation needs.

1.2.2 Produce service specifications for integrated rehabilitation care for people with a chronic neurological disorder to include the following:

- practitioners to lead and coordinate holistic rehabilitation needs assessments, and agree and oversee delivery of rehabilitation plans
- advocacy services (for people who need them)
- information, advice, education and training to support all aspects of rehabilitation
- play therapies that facilitate the delivery of rehabilitation interventions for children
- environmental adaptations
- equipment, assistive devices and compensatory aids
- pain and fatigue management interventions
- exercise and physical activity programmes and other interventions for muscle strength and physical functioning and general physical health
- gait training, exercises and equipment for stability, mobility and limb function
- interventions for:
    - emotional health and mental wellbeing

    - cognitive function
    - speech, language and communication
    - eating, drinking and swallowing
- occupational therapy and skills-based learning
- other interventions to support engagement in education, employment, social and leisure activities, parenting, family life, friendships and intimate relationships.

For a short explanation of why the committee made these recommendations and how they might affect services, see the rationale and impact section on commissioning rehabilitation services and service specifications.

Full details of the evidence and the committee's discussion are in evidence review A: rehabilitation delivery and evidence review I: clinical case management.

1.3 Building local capacity and expertise

1.3.1 Ensure collaboration between commissioning bodies from healthcare, social care and other relevant community service providers, for example education services for children.

1.3.2 Ensure there are separate local service level agreements in place for the provision of mental health services for adults, and for children and young people, with a chronic neurological disorder.

1.3.3 Build capacity for mental health services for people with a chronic neurological disorder through local workforce skills development and communication protocols between different services involved in rehabilitation.

1.3.4 Ensure that GPs and other primary care practitioners know how to recognise emerging rehabilitation needs because of an existing chronic neurological disorder, and know when and how to refer people to rehabilitation specialists. For example, using expertise from specialist neurorehabilitation services and maintaining up-to-date information on options for local rehabilitation services.

1.3.5 Ensure that healthcare and social care practitioners know how to commission high-cost specialist equipment and services.

1.3.6 If availability of specialist neurorehabilitation services is restricted in some areas or for some people (including for people living in rural areas or with rare conditions) collaborate within and between integrated care systems to:

- enable access to specialist care where possible
- share specialist advice and expertise with non-specialist services
- explore provision of general community rehabilitation services supported by specialist services.

1.3.7 Consider funding social and leisure group activities to support rehabilitation in the community. When doing this take account of the following:

- people do not always want to socialise with people who have the same condition as them
- some people may want to socialise with others facing similar challenges
- younger people may feel more comfortable socialising with their peers
- people with a functional neurological disorder may not find a group approach helpful
- some people may feel more comfortable in social and leisure groups for the wider community if they are reassured these groups will be accessible to them.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on building local capacity and expertise.

Full details of the evidence and the committee's discussion are in evidence review A: rehabilitation delivery, evidence review B: identification and referral, evidence review H: emotional health and mental wellbeing and evidence review K: access to support for education, employment and social participation.

1.4 Providing responsive services

1.4.1 Service providers should communicate and collaborate, including across specialities, and with the third sector and private sector, to ensure care pathways are responsive to people's needs, including when people are moving between services.

1.4.2 Set up simple referral and re-referral (including self-referral) mechanisms that allow people with a chronic neurological disorder to access rehabilitation needs assessments, interventions and support when they need it, including after they have been discharged from rehabilitation services.

1.4.3 Consider sharing rehabilitation needs assessments to improve the speed, efficiency and responsiveness of service provision (for example, use of trusted assessments).

1.4.4 Ensure rehabilitation services have the capacity and expertise to respond in a timely and proportionate way to people experiencing:

- changing needs outside of planned interventions
- rapidly emerging new needs.

For a short explanation of why the committee made these recommendations and how they might affect services, see the rationale and impact section on providing responsive services.

Full details of the evidence and the committee's discussion are in evidence review A: rehabilitation delivery and evidence review B: identification and referral.

Assessing rehabilitation needs and goal setting

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1.5 Early discussion about prognosis and rehabilitation

1.5.1 Ensure that the need for rehabilitation is identified as early as possible in people with a suspected or confirmed chronic neurological disorder.

1.5.2 Offer the person, and their family or carers, if appropriate, a discussion soon after injury or diagnosis (before symptoms or impairments may have emerged) about their prognosis and how their rehabilitation needs may emerge or change over time.

1.5.3 If the person does not wish to discuss their prognosis, offer further opportunities at a later date for this discussion.

1.5.4 Following diagnosis or initial treatment for a chronic neurological disorder, the responsible clinician should give the person a contact for rehabilitation, and inform their GP of this contact.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on early discussion about prognosis and rehabilitation.

Full details of the evidence and the committee's discussion are in evidence review A: rehabilitation delivery and evidence review B: identification and referral.

1.6 Hospital discharge

Healthcare and social care practitioners should follow our general guidelines about transferring from hospital to home:

- Transition between inpatient hospital settings and community or care home settings for adults with social care needs

1.6.1 At hospital discharge, ensure there is both a key clinical contact for medical advice and a contact for rehabilitation.

1.6.2 If rehabilitation has begun or elements of a rehabilitation needs assessment have been carried out before hospital discharge, the inpatient multidisciplinary team, and community and primary care practitioners should jointly agree who will be the contact for rehabilitation. This person may be a clinical nurse specialist, GP, rehabilitation physician, special educational needs coordinator, allied health professional, family support worker, social worker, case manager, disability paediatrician or speciality-specific coordinator, for example, a neuro navigator.

1.6.3 At the earliest opportunity, arrange for the provision of any equipment and environmental adaptations the person needs at home, to support their rehabilitation and prevent delays to discharge.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on hospital discharge.

Full details of the evidence and the committee's discussion are in evidence review A: rehabilitation delivery and evidence review B: identification and referral.

1.7 When to undertake, or make a referral for, holistic rehabilitation needs assessment

1.7.1 Think about undertaking, or making a referral for, holistic rehabilitation needs assessment:

- as soon as a diagnosis is established or
- based on symptoms or impairment (even if a chronic neurological disorder is suspected but not yet confirmed).

1.7.2 Make a brief assessment of the person's social, psychological, emotional, cognitive and communication needs, as well as their physical health and level of impairment, to help decide whether holistic assessment is needed.

1.7.3 If the practitioner in charge of the person's care decides holistic rehabilitation needs assessment is not needed, they should tell the person how to ask for an assessment if their symptoms or level of functioning changes (for children this may be at key developmental stages).

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on when to undertake, or make a referral for, holistic rehabilitation needs assessment.

Full details of the evidence and the committee's discussion are in evidence review B: identification and referral.

1.8 Holistic rehabilitation needs assessment

Healthcare and social care practitioners should follow our general guidelines about supporting people to make decisions about their health and social care:

- Advocacy services for adults with health and social care needs
- Babies, children and young people's experience of healthcare (includes section on advocacy and support)
- Decision making and mental capacity

Support and advocacy for making decisions during rehabilitation

1.8.1 Ensure the person is supported to make decisions about their health and social care, especially if they may have complex communication or cognitive needs or 'invisible' symptoms or impairments. This may include involving family, carers or others close to the person as representatives (if the person agrees) or formally appointed advocates.

Initiating holistic rehabilitation needs assessment and who to involve

1.8.2 If a referral for a specific functional needs assessment is received, offer holistic rehabilitation needs assessment unless:

- there is an active and current holistic needs assessment already in place, **and**
- it is clear that any new rehabilitation needs can be met with the specific functional needs assessment.

1.8.3 The person initiating holistic rehabilitation needs assessment (which may be the responsible clinician) should:

- identify and contact the likely healthcare and social care practitioners who might be needed **and**
- agree with the practitioners who is best placed to lead on and coordinate the assessment (the lead practitioner) **and**
- make onward referrals to other healthcare and social care practitioners where other needs that are not linked to rehabilitation are identified.

1.8.4 The lead practitioner should seek input from healthcare and social care practitioners and other practitioners (including teachers, social prescribers and equipment providers) to inform the assessment.

1.8.5 Discuss who is important to the person and if and how they would like them to be involved in their rehabilitation. Make sure the other people agree to their role in helping to deliver rehabilitation.

1.8.6 Complete holistic rehabilitation needs assessment in partnership with the person and those people important to their rehabilitation (see recommendation 1.8.5).

1.8.7 Do not delay starting rehabilitation interventions while undertaking holistic needs assessment.

What to cover

1.8.8 Ask the person about:

- their background, relationships, work, education, meaningful activities, spiritual and religious practices, and hobbies and interests
- their activities of daily living (including self-care skills and domestic and leisure activities) and how this has changed or is changing
- developmental milestones and play in the case of children
- what would motivate them to engage in rehabilitation and what is most important in their life
- environmental and wider social factors that might encourage or prevent them from taking part in rehabilitation (for example, access

to community resources and equipment for rehabilitation and housing).

1.8.9 In addition to their neurological condition or injury, think about how other health conditions, including mental health conditions, may affect their rehabilitation.

1.8.10 Encourage the person to talk freely about how their life has been impacted by their neurological condition.

1.8.11 Remember that some people may have 'invisible' or less easily recognisable symptoms or impairments, or they may lack awareness of their condition and may struggle to articulate their rehabilitation needs.

1.8.12 Assess the person's need for information, advice and training about how their condition or injury is impacting on their level of functioning and ability to carry out their usual day-to-day activities.

1.8.13 Identify the rehabilitation interventions that may help the person, and their family or carers, if appropriate, to prepare psychologically and physically for future changes to impairment and functioning. This is especially important if the person has a rapidly progressing condition.

1.8.14 Assess the following areas of function, symptoms and impairment:

- pain (see the section on pain management)
- fatigue (see the section on fatigue)
- physical activity and exercise (see the section on physical activity and exercise)
- stability, mobility and limb function (see the section on stability, mobility and limb function)
- emotional health and mental wellbeing (see the section on emotional health and mental wellbeing)
- cognitive function (see the section on cognitive function)
- speech, language and communication (see the section on speech, language and communication)

- eating, drinking and swallowing (see the section on eating, drinking and swallowing)
- independent living needs, equipment and environmental adaptations (see the section on independent living, equipment and environmental adaptations).

1.8.15 As part of the holistic needs assessment, learn how the person’s functioning, abilities and needs vary, or are likely to vary:

- in different real-life environments, for example, their home, place of education or work, and places they visit such as shops or leisure centres
- at different times of the day and from day to day
- over the longer term.

1.8.16 Assess the need for rehabilitation to enable the person to participate in every aspect of their daily life. See the section on rehabilitation to support education, work, social and leisure activities and relationships.

1.8.17 Do not exclude someone from any aspect of holistic needs assessment based on their memory or learning difficulties.

1.8.18 Make reasonable adjustments and adaptations to enable a person with memory or learning difficulties to engage in rehabilitation.

Related assessments

1.8.19 Use the NHS continuing healthcare checklist to determine if someone is eligible for continuing NHS healthcare at home.

1.8.20 Discuss with the person, and their family or carers, if appropriate, whether they have social care needs and whether a social care needs assessment is required. For more information, see NICE's guideline on social work with adults experiencing complex needs.

1.8.21 For children and young people with severe complex needs, assess their rehabilitation needs as part of an education, health and care plan

(EHCP), which should cover special educational needs, social care and healthcare, including rehabilitation. For more information, see NICE's guideline on disabled children and young people up to 25 with severe complex needs.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on holistic rehabilitation needs assessment.

Full details of the evidence and the committee's discussion are in evidence review A: rehabilitation delivery, evidence review B: identification and referral, evidence review C: assessment, planning and review, evidence review D: personal care and activities of daily living and evidence review G: cognitive function.

1.9 Goal setting

1.9.1 Explain the process and reasons for goal setting to the person.

1.9.2 Work collaboratively with the person to agree long-term rehabilitation goals, broken down into short-term steps, that focus on what is most important to the person.

1.9.3 Use age-specific approaches to engage children and young people in goal setting conversations.

1.9.4 Agree goals based on the person's wishes and aspirations that:

- focus on optimising participation in the most important aspects of the person's life
- aim to improve, maintain or reduce deterioration in functioning over time
- incorporate the need for psychological adaptation, acceptance and recovery
- take account of developmental challenges, in the case of children and young people.

1.9.5 When agreeing goals discuss the potential for both positive and negative outcomes, including the impact that future changes in the person's functioning may have and the need to review goals regularly in this context.

1.9.6 Allow sufficient time during consultations with the person, and their family or carers, if appropriate, for goal setting, and later for rehabilitation planning.

1.9.7 Tailor the timeframe for reviewing goals to the person's condition, situation and nature of the goal.

1.9.8 Frequently adjust rehabilitation goals and plans for children and young people in response to their growth and developmental stage.

For education, training and work

1.9.9 Ask the person about their aspirations and goals in relation to staying in, returning to, or leaving work, education or training.

1.9.10 Use this information, together with the person's likely developmental trajectory in the case of a child or young person, when setting education and work goals with them.

1.9.11 Work with the person to identify their strengths, motivations and rehabilitation needs in relation to work, education or training provision.

1.9.12 Review the person's goals connected to work, education or training whenever their rehabilitation needs are being reassessed.

See also the sections on rehabilitation to support education for children and young people, and rehabilitation and the workplace.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on goal setting.

Full details of the evidence and the committee's discussion are in evidence review C: assessment, planning and review and evidence review K: access to support for education, employment and social participation.

Rehabilitation planning and delivery

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1.10 Agreeing and delivering a coordinated rehabilitation plan

1.10.1 Based on the person's holistic rehabilitation needs assessment and their goals, agree a personalised rehabilitation plan (based on interventions in sections on rehabilitation to maintain, improve or support function and support education, work, social and leisure activities, and relationships) with the person, those people important to their rehabilitation (see recommendation 1.8.5) and the healthcare and social care practitioners involved in their assessment or care.

1.10.2 When agreeing the interventions and approaches that will constitute the rehabilitation plan, think about and include in the plan:

- the timing, intensity and frequency of interventions (as appropriate)
- how interventions relate to, and interact with, each other
- modifying interventions in line with factors such as developmental age and cognitive abilities
- the person's rehabilitations goals and how the interventions will deliver these goals.

1.10.3 Focus on interventions for optimising or maintaining the person's functioning and abilities, even when they have a time-limited prognosis or the potential for improvement appears to be limited.

1.10.4 Deliver rehabilitation interventions in settings that are appropriate to the person's rehabilitation goals and meet their preferences. This may be at home, school, work or community settings, or remotely, where appropriate.

1.10.5 If the person is in work, education or training, collaborate with their employer, education setting or adult learning support centre to agree and deliver rehabilitation interventions that are relevant to the tasks and activities the person will be undertaking.

1.10.6 Regularly review education support plans for adults where these cover rehabilitation provision, especially where the person's chronic neurological condition is progressive or fluctuating.

See also the sections on rehabilitation to support education for children and young people, and rehabilitation and the workplace.

1.10.7 Practitioners involved in delivering the rehabilitation plan should work together to ensure timely and joined-up delivery of the interventions and approaches.

1.10.8 Discuss and agree aspects of rehabilitation that may be delivered at a later date as well as what might inform decisions about discontinuation of interventions.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on agreeing and delivering a coordinated rehabilitation plan.

Full details of the evidence and the committee's discussion are in evidence review A: rehabilitation delivery, evidence review B: identification and referral, evidence review C: assessment, planning and review and evidence review K: access to support for education, employment and social participation.

1.11 Assigning a single point of contact and assessing the person's ability to coordinate their own care

Healthcare and social care practitioners should also see our guidelines about a single point of contact for people with motor neurone disease, Parkinson's disease, multiple sclerosis in adults and people with brain tumours:

- Motor neurone disease: assessment and management (1.2.4)
- Parkinson's disease in adults (1.1.6)
- Multiple sclerosis in adults: management (1.3.1)
- Brain tumours (primary) and brain metastases in over 16s (1.9.5)

1.11.1 As part of the person’s rehabilitation plan, assign them a single point of contact to:

- help them understand and navigate rehabilitation services
- coordinate their rehabilitation plan
- support them in accessing rehabilitation services, if needed
- refer them to other services, if needed.

1.11.2 Assess the person’s ability, or that of their family or carers, if appropriate, to self-manage their rehabilitation and agree the most appropriate type of single point of contact for their rehabilitation. This may be a key contact, key worker or complex case manager.

1.11.3 Review the person's ability to self-manage their rehabilitation if significant difficulties are observed or reported, and change the type of single point of contact, if needed.

1.11.4 Think about the level of rehabilitation coordination, navigation and support the person needs before agreeing the single point of contact. Agree whether specialist clinical knowledge is necessary and the relative importance of a broad and detailed knowledge of local service availability.

1.11.5 Consider assigning a key worker if the person has:

- impaired cognitive or executive function that impacts on their ability to self-manage their condition or navigate rehabilitation services
- an unpredictable or rapidly changing neurological condition
- multiple rehabilitation needs that require rehabilitation across multiple services and areas of care
- the potential to develop new needs around accessing care and there are associated family support needs, (for example in the case of a child or young person moving between education settings).

1.11.6 Consider assigning a complex case manager if the person has severe, complex and long-term rehabilitation needs and:

- impaired cognitive or executive function that severely impacts their ability to self-manage their condition or navigate rehabilitation services **or**
- is unable to advocate for themself and has no-one to advocate for them (some people may have a legal right to advocacy) **or**
- has serious comorbidities (for example, poorly controlled diabetes or epilepsy), a learning disability, misuses drugs or alcohol or has neurobehavioural symptoms that place them at risk of harm to themself or others.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on assigning a single point of contact and assessing the person's ability to coordinate their own care.

Full details of the evidence and the committee's discussion are in evidence review A: rehabilitation delivery, evidence review B: identification and referral and evidence review I: clinical case management.

1.12 After the rehabilitation plan

1.12.1 Update the person about their single point of contact (key contact, key worker or complex case manager) if this is going to change after rehabilitation has ended and make sure they know how to get in touch if their symptoms or level of impairment changes.

1.12.2 Agree if a follow-up appointment is needed, taking into account:

- any reasonably anticipated future rehabilitation needs (including those associated with either deterioration or improvement in the person's condition or around end-of-life care)
- the person's ability, or that of the family or carers, to get in contact if their needs change
- unpaid support around the person, including from their family, carers and social network

- ongoing support and care from healthcare and social care services including from the third sector.

1.12.3 Decide which practitioner(s) will be involved in the follow-up, for example, care coordinator, nurse specialist, key therapist, healthcare assistant or support worker.

1.12.4 Plan follow-up for children at key neurodevelopmental stages, recognising that rehabilitation needs and goals may change over time and that new symptoms may emerge.

1.12.5 Ensure people have access to the right equipment, technology and advice before rehabilitation ends, to help them prepare for changes that may happen in the future.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on after the rehabilitation plan.

Full details of the evidence and the committee's discussion are in evidence review A: rehabilitation delivery.

Information, advice and learning as part of rehabilitation

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1.13 Information, advice and learning as part of rehabilitation

1.13.1 Give personalised information to people with a chronic neurological disorder, and their family or carers, if appropriate, about:

- their condition and rehabilitation needs, including any anticipated future needs
- how to access rehabilitation services and social care
- how to get advice about work and education, housing, benefits and legal support
- voluntary and community organisations, local support groups, national charities and other third sector organisations that can provide further information and support.

1.13.2 Explain what financial support is available to assist with rehabilitation in relation to activities of daily living, travel, and social and leisure activities, for example, travel support, provision of wheelchairs and personal assistance via personal budgets and direct payments.

1.13.3 Explain to the person or their advocate that they can request an assessment of care and support needs from their local authority.

1.13.4 Continue to offer personalised information and advice as and when the person's rehabilitation needs or circumstances change, for example, at discharge from hospital or rehabilitation services, at different life stages or as their condition progresses.

1.13.5 Consider joined-up education and training interventions for the person, and their family or carers, if appropriate, to deliver different elements of their rehabilitation plan at the same time, for example, training in cognitive strategies alongside use of equipment for independent living, both of which might happen in the person’s home.

1.13.6 Help the person decide what and how to communicate to others about their condition and rehabilitation needs. Think about:

- the use of a disability passport
- information to share with community staff (especially when adjustments to services are required)
- information to share socially with others.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on information, advice and learning as part of rehabilitation.

Full details of the evidence and the committee’s discussion are in evidence review A: rehabilitation delivery, evidence review B: identification and referral and evidence review K: access to support for education, employment and social participation.

Rehabilitation to maintain, improve or support function

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1.14 Pain management

1.14.1 Ask about pain as part of holistic rehabilitation needs assessment.

1.14.2 Proactively support people in managing their pain and ensure that they have adequate analgesia to facilitate rehabilitation.

1.14.3 Think about pain management when discussing and agreeing rehabilitation goals and plans, taking into account that the following interventions may reduce pain or improve pain management:

- fatigue management approaches
- physical exercise and activity
- interventions for stability, mobility and limb function (including postural management strategies)
- psychological interventions for low mood, anxiety or support with acceptance and adjustment
- interventions to support independent living, equipment and environmental adaptations.

See NICE's guideline on chronic pain (primary and secondary) in over 16s: assessment of all chronic pain and management of chronic primary pain and seek specialist pain management input for children and young people with chronic pain.

See NICE's guideline on neuropathic pain in adults: pharmacological management in non-specialist settings and seek specialist pain management input for children and young people and for adults in specialist settings.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on pain management.

Full details of the evidence and the committee's discussion are in evidence review C: assessment, planning and review, evidence review D: personal care and activities of daily living, evidence review E: stability, mobility and upper limb function, evidence review H: emotional health and mental wellbeing, evidence review J: fatigue management and evidence review O: access to physical activity.

1.15 Fatigue

Healthcare and social care practitioners should also follow our recommendations about fatigue in the following guideline for people with multiple sclerosis in adults:

- Multiple sclerosis in adults: management (1.5.3 to 1.5.23)

Assessment

1.15.1 Ask about fatigue as part of holistic rehabilitation needs assessment and whenever rehabilitation is being discussed.

1.15.2 Find out how fatigue impacts on the person's daily life and how their usual day-to-day activities impact on their fatigue, when the person is feeling at both their best and worst.

1.15.3 Take into account the person's awareness and understanding of their fatigue and its impact, when assessing and managing fatigue.

1.15.4 Help the person's family and carers to understand how fatigue affects the person and how to respond to this appropriately.

1.15.5 Check for treatable factors that may be affecting fatigue, for example, mood difficulties, sleep problems, nutritional problems, abnormal endocrine function, medication and some neurological symptoms, including vestibular symptoms. Refer for treatment, as necessary.

Interventions

1.15.6 Offer a fatigue management approach, if needed, that prioritises what is important to the person, meets their goals and is integrated within their overall rehabilitation plan. This could include:

- pacing and other energy-conservation strategies
- cognitive behavioural therapy
- appropriate physical activity.

1.15.7 Encourage appropriate physical activity for longer-term general health benefits even in the presence of fatigue.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on fatigue.

Full details of the evidence and the committee's discussion are in evidence review J: fatigue management.

1.16 Physical activity and exercise

Healthcare and social care practitioners should also follow our recommendations about physical activity and exercise in the following guidelines for people with motor neurone disease, Parkinson's disease and multiple sclerosis in adults:

- Motor neurone disease: assessment and management (1.8.5 to 1.8.9)
- Parkinson's disease in adults (1.7.2 to 1.7.4)
- Multiple sclerosis in adults: management (1.4.1)

1.16.1 Develop an exercise and physical activity programme with the person to optimise their muscle strength and physical functioning, if needed, and:

- take into account their executive function and levels of fatigue and pain
- consider supervised exercises
- agree a clinically relevant exercise dose (frequency, duration and intensity).

1.16.2 Discuss and agree outdoor or indoor activities that the person could do to maintain or improve their general physical health. Be led by the preferences of the person and think about possible suitable activities.

1.16.3 Help the person to participate in, and sustain engagement with, physical activity using behaviour change strategies if needed. This may require a family-centred approach.

1.16.4 Consider the following approaches to encourage lifelong behaviour change around physical activity:

- cognitive behavioural therapy
- self-determination theory
- social context theory
- motivational interviewing or coaching techniques.

1.16.5 Discuss any barriers preventing the person from achieving their physical activity goals and work together to overcome these. Barriers could relate to:

- the need for support, which may be practical, physical or cognitive
- cultural or socioeconomic factors
- availability of suitable facilities to undertake physical activity.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on physical activity and exercise.

Full details of the evidence and the committee's discussion are in evidence review E: stability, mobility and upper limb function and evidence review O: access to physical activity.

1.17 Stability, mobility and limb function

1.17.1 If the person has problems with stability, mobility, or upper or lower limb function, work with them to develop specific and targeted training and exercises. This may include:

- functional activity including task-based training (see also recommendation 1.22.6)
- gait training, for example, treadmill gait training, with or without body weight support
- balance exercises, for example, core stability exercises and perturbation-based balance training
- exercises involving sensorimotor tasks
- wheelchair skills training

- use of robotics, an exoskeleton, or a combined approach (where available)
- hydrotherapy (where available)
- exercise and training delivered through play therapy (for children).

1.17.2 Provide equipment, including orthoses and splinting, to support movement and protect against injury and secondary impairment.

1.17.3 Think about using gaming modalities or virtual reality to help engagement in training and exercises to improve stability, mobility or limb function.

1.17.4 Incorporate training and exercises for stability, mobility or limb function into the person’s day-to-day activities, at home and in the community.

1.17.5 Agree targeted training and exercises that the person can continue to undertake independently, or with the support of family or carers, as part of their day-to-day activities.

1.17.6 As part of rehabilitation to restore or maintain limb structure and function, provide serial or removable casting.

1.17.7 Consider 24-hour postural management strategies (for example regular positional changes, bed positioning, wheelchair and seating systems, and splints) if the person is not able, or is less able, to sit up or stand up unaided or move independently and is at risk of skin breakdown, pain, sleep disturbance, respiratory dysfunction or muscle or joint contracture.

Treadmill gait training

1.17.8 When planning treadmill gait training, take into account that it may also improve the person’s exercise capacity during the training period and motivate them to be physically active over the longer term.

1.17.9 If the person has a progressive neurological condition, think about low- or intermediate-frequency treadmill gait training over a longer period to optimise their mobility and exercise capacity.

1.17.10 Consider robot-assisted treadmill gait training where this equipment is available to further improve mobility and exercise capacity.

1.17.11 When stopping supervised treadmill gait training, support the person to maintain their exercise capacity, as appropriate.

Electrical stimulation

1.17.12 Consider neuromuscular electrical stimulation in addition to muscle strengthening exercise and functional activity.

1.17.13 If the person has muscle weakness of the lower limbs, consider functional electrical stimulation in addition to gait training.

Interventions for vestibular problems

1.17.14 If vestibular problems are suspected, provide central and peripheral vestibular assessment, and, if needed, exercises or procedures such as gaze stability exercises or canalith repositioning manoeuvres.

For a short explanation of why the committee made this recommendation/these recommendations and how they might affect practice, see the rationale and impact section on stability, mobility and limb function.

Full details of the evidence and the committee's discussion are in evidence review D: personal care and activities of daily living and evidence review E: stability, mobility and upper limb function.

1.18 Emotional health and mental wellbeing

Principles of assessment, referral and intervention selection

1.18.1 Think about the person's emotional health and mental wellbeing throughout rehabilitation, paying particular attention to key life stages.

1.18.2 Be aware that neurological injuries can result in abrupt fluctuations in a person's emotional state (known as emotional lability) (if the person has motor neurone disease (MND), see also the recommendation on emotional lability in the section on recognition and referral in NICE's guideline on MND). If emotional lability is suspected, refer for appropriate management interventions (if the person has multiple sclerosis (MS), see also the section on emotional lability in NICE's guideline on MS in adults) and take into account when planning rehabilitation.

1.18.3 Take into account the person may need time and support to adjust to, and accept, any changes caused by their condition, and incorporate these changes into, or alongside, their sense of identity.

1.18.4 When assessing a person's emotional health and mental wellbeing, recognise that emotional health and mental wellbeing may be adversely impacted by unmet needs in other areas of rehabilitation. If this is the case, follow other recommendations in this guideline to meet those unmet needs.

1.18.5 Take account of family and carers and other social networks when agreeing the most appropriate interventions to improve or sustain emotional health and mental wellbeing.

1.18.6 Ensure that goals and interventions for emotional health and wellbeing are agreed within the context of other rehabilitation goals and interventions.

1.18.7 Make referrals to emotional health and mental wellbeing services with the most appropriate expertise, based on the person's needs and circumstances. Assessments or interventions may be provided by:

- neurorehabilitation services
- mental health services
- third sector providers (for example, Headway or other charities, community groups and social enterprises)
- education services (for children and young people, those delivered by a special educational needs coordinator or through an emotional literacy support assistant programme, for example).

1.18.8 Where assessments for, or interventions to improve, emotional health and mental wellbeing are provided by a separate service to other rehabilitation services, ensure there is ongoing two-way communication and coordination between services.

1.18.9 Enable the person to opt in and opt out of services for emotional health and mental wellbeing, as needed in order to manage their fluctuating needs. The arrangement may be direct with the service or via a single point of contact.

Interventions

1.18.10 If the person has low mood or anxiety, or is distressed by, or having difficulties adjusting to the impact of their neurological condition, consider cognitive behavioural therapy (CBT), mindfulness-based talking therapy or acceptance-based interventions.

1.18.11 Where low mood, anxiety or difficulties adjusting to the impact of a chronic neurological condition present barriers to participation in activities of daily living, consider psychoeducation and motivational interviewing.

1.18.12 If the person displays behaviours that challenge, consider neurobehavioural approaches, for example, positive behaviour support.

1.18.13 If the person has difficulty engaging in talking therapies because of cognitive or communication problems, or where speaking is not the person's preferred way of communicating, consider creative therapies.

1.18.14 Offer individual or group interventions for low mood, anxiety and adjustment difficulties, or a mixture of both, based on the person's needs and preferences.

1.18.15 When delivering talking therapies, take into account the person's cognitive and communication needs and other impacts of their neurological condition. This may require adjustments to:

- therapy techniques, for example, using memory or communication aids
- the number, length and frequency of sessions
- type of intervention (for example, CBT or mindfulness) and form of delivery (for example, online or face-to-face interventions).

1.18.16 Treat diagnosed post-traumatic stress disorder, anxiety and depression in adults with chronic neurological disorders, and depression in children and young people with a chronic neurological disorder as part of their rehabilitation, and based on NICE's guidelines on:

- post-traumatic stress disorder
- social anxiety disorder
- generalised anxiety disorder and panic disorder in adults
- depression in adults
- depression in adults with a chronic physical health problem
- depression in children and young people.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on emotional health and mental wellbeing.

Full details of the evidence and the committee's discussion are in evidence review H: emotional health and mental wellbeing.

1.19 Cognitive function

Principles

1.19.1 Help the person, and their family or carers, if appropriate, to understand, build insight and awareness of, and adjust to any difficulties with cognitive function.

1.19.2 Support the person to adjust to cognitive changes before or alongside rehabilitation.

Assessment

1.19.3 Assess for cognitive strengths and weaknesses across the following domains:

- orientation
- processing speed
- visual, spatial and perceptual cognition
- language
- attention and working memory
- learning and memory
- executive function
- social cognition.

1.19.4 Use both standard cognitive tests and functional assessments when assessing the person's cognitive strengths and weaknesses.

1.19.5 When deciding which assessment techniques to use and how to interpret any results, take into account the following:

- the person's cognitive ability before neurological injury or development of their neurological disorder
- the demands of the tests and functional assessments and the environment in which they are being undertaken
- how symptoms such as fatigue, low mood or pain may affect testing and assessment
- the impact of any other health conditions on testing and assessment.

1.19.6 Explain the format and purpose of any cognitive tests before using them, unless this would invalidate the test.

1.19.7 Plan cognitive rehabilitation based on the results of the cognitive assessment, taking into account any interaction between the domains listed in recommendation 1.19.3, as well as the person's preferences and retained cognitive skills.

Interventions

1.19.8 Provide advice about ways to optimise or maintain cognitive function, such as taking up new hobbies, getting out of the house to socialise, playing games or puzzles, or using brain training exercises.

1.19.9 Offer advice and support to help the person to minimise risk factors for cognitive decline and help maintain existing cognitive function. For example, advice about physical activity, smoking cessation, blood pressure control and sleep.

1.19.10 Discuss ways to help the person to compensate for, and manage, difficulties with memory and learning in daily life. For example, cueing and prompting by others, changes to the person's environment and use of compensatory aids such as smart phone apps, paper diaries, electronic calendars, video games, virtual reality and other computer-based exercises.

1.19.11 To improve executive function discuss and agree internal and external compensatory strategies and changes to the person's environment.

1.19.12 Explain compensatory strategies to the person's family or carers so they can offer support outside of therapy sessions.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on cognitive function.

Full details of the evidence and the committee's discussion are in evidence review C: assessment, planning and review and evidence review G: cognitive function.

1.20 Speech, language and communication

Healthcare and social care practitioners should also follow our recommendations about communication in the following guidelines for people with motor neurone disease and Parkinson's disease:

- Motor neurone disease: assessment and management (1.11.1 to 1.11.6)
- Parkinson's disease in adults (1.7.7 to 1.7.9)

1.20.1 Ask about difficulties with speech, language and communication as part of holistic rehabilitation needs assessment.

1.20.2 If difficulties with speech, language and communication are suspected, offer an initial screening for impairment by a speech and language therapist.

1.20.3 Following initial screening, carry out further assessment, if needed. Do this urgently if the person has a severe speech, language or communication impairment, for example, where it is having a significant impact on their usual day-to-day activities.

1.20.4 Offer therapy for any speech, language and communication needs that are identified, focusing on the person's rehabilitation goals (see the section on rehabilitation goals).

1.20.5 If the person has a severe speech, language or communication impairment, refer them for assessment for alternative and augmentative communication equipment, if clinically indicated.

1.20.6 Consider teaching functional speech, language and communication skills that the person can practise and use in real-life environments.

1.20.7 Consider providing a speech and language therapy-led education and training programme in communication skills for family, carers or others close to the person.

1.20.8 Offer early referral for voice banking to people with, or who are likely to experience, voice loss.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on speech, language and communication.

Full details of the evidence and the committee's discussion are in evidence review F: speech, language and communication and evidence review K: access to support for education, employment and social participation.

1.21 Eating, drinking and swallowing

Healthcare and social care practitioners should also follow our recommendations about eating, drinking and nutrition in the following guidelines for people with motor neurone disease and Parkinson's disease:

- Motor neurone disease: assessment and management (1.10.1 to 1.10.10)
- Parkinson's disease in adults (1.7.10 to 1.7.15)

Assessment and management

1.21.1 Assess oral hygiene and support the person to follow an effective mouthcare regime, if needed

1.21.2 Provide saliva management, if needed. (If the person has motor neurone disease (MND), see also the section on saliva problems in NICE's guideline on MND or if the person has Parkinson's disease, see also the section on drooling of saliva in NICE's guideline on Parkinson's disease in adults).

1.21.3 A healthcare professional trained in dysphagia should assess the person's ability to eat, drink and swallow if there are indicators of dysphagia. For indicators in adults, see the section on oral nutrition support in hospital and the community in NICE's guideline on nutrition support for adults.

1.21.4 To prevent deterioration in, or sustain or improve, the person's ability to eat, drink and swallow, provide one or more of the following:

- advice on the best position and posture for eating and drinking
- speech and language therapy-led interventions to improve swallowing safety, including swallowing exercises and manoeuvres

  (for example, the supraglottic swallow, the effortful swallow and Masako manoeuvres)
- adapted equipment for eating and drinking, including cutlery and crockery, for example one-way straws and angled cups
- sensory interventions, for example, for taste, smell and thermal stimulation, particularly if the person is not allowed to have any food or drink by mouth.

1.21.5 Modify food and fluids, as directed by a speech and language therapist, taking into account the person's comfort, safety and preferences.

1.21.6 Where modified food and fluids are provided, regularly review the person's ability to eat, drink and swallow.

1.21.7 Provide nutrition support if the person is malnourished, or at risk of malnutrition, and has inadequate or unsafe oral intake, in line with their preferences or, if they lack capacity, their best interests or advance directives. For recommendations on screening, indications and interventions for nutrition support, see NICE's guideline on nutrition support for adults.

1.21.8 Only introduce feeding mechanisms that restrict the person's choice and autonomy, such as enteral tube feeding:

- when absolutely necessary and
- provided consent is obtained or, if they lack capacity, it is in line with their best interests or advance directives.

Principles of care

1.21.9 Have timely discussions with the person to help maintain their autonomy about what, and when, to eat and drink.

1.21.10 Offer advice to the person, and their family or carers, if appropriate, about the risks and benefits of eating and drinking, and training in how to use any adapted equipment.

1.21.11 If the person decides to eat and drink by mouth whilst understanding the risks involved, respect their choice and provide safety guidance and advice.

1.21.12 Anticipate and address future escalation of risks and needs around eating and drinking, for example, risk of aspiration.

1.21.13 Undertake advance care planning to capture the person's future preferences regarding nutrition, if appropriate.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on eating, drinking and swallowing.

Full details of the evidence and the committee's discussion are in evidence review D: personal care and activities of daily living.

1.22 Independent living, equipment and environmental adaptations

Healthcare and social care practitioners should follow our guidelines about home care and preventing falls for older people who also have a chronic neurological disorder:

- Home care: delivering personal care and practical support to older people living in their own homes
- Falls in older people: assessing risk and prevention

They should also follow our recommendations about equipment and adaptations to aid independence in activities of daily living for people with motor neurone disease and multiple sclerosis in adults:

- Motor neurone disease: assessment and management (1.9.1 to 1.9.8)
- Multiple sclerosis in adults: management (1.2.15)

And should follow recommendations about occupational therapy for people with Parkinson’s disease and multiple sclerosis in adults:

- Parkinson’s disease in adults (1.7.5 to 1.7.6)
- Multiple sclerosis in adults: management (1.2.16 and 1.5.44)

Supporting independence with activities of daily living

1.22.1 Assess the person’s ability to carry out activities of daily living, including the impact of their condition on this.

1.22.2 Teach and support the person to use compensatory aids to improve or maintain independence with activities of daily living (see also recommendation 1.19.10 in the section on cognitive function).

1.22.3 Support the person to optimise independence and aid participation in daily life. This may include providing equipment, such as a wheelchair or other assistive devices, for postural support and movement.

Occupational therapy and skills-based learning

1.22.4 Consider early access to occupational therapy to develop, maintain or prevent deterioration in skills for independent living.

1.22.5 Provide occupational therapy (if needed) within settings and using scenarios that are appropriate to the person’s rehabilitation goals.

1.22.6 When delivering skills-based learning or task-based training, use error-based or errorless techniques depending on the person’s cognitive strengths and weaknesses and the skill or task the training is focusing on.

Environmental adaptations, assistive technology and equipment

1.22.7 Identify and address any environmental barriers to activities of daily living in the home or residential setting (for example moving furniture or commonly used cooking or bathing items to a more accessible place) and assess the need for moving and handling equipment (for example a bed hoist) and environmental adaptations.

1.22.8 Give the person advice and support to access, or to access funding for, equipment, assistive technology or environmental adaptations in their home or residential setting, education or workplace setting where this is not available from the NHS. This may include funding or provision from the government, their local authority or the voluntary sector.

1.22.9 Work collaboratively with required services to ensure timely delivery of equipment and environmental adaptations.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on independent living, equipment and environmental adaptations.

Full details of the evidence and the committee's discussion are in evidence review B: identification and referral, evidence review D: personal care and activities of daily living and evidence review K: access to support for education, employment and social participation.

Rehabilitation to support education, work, social and leisure activities, and relationships

People have the right to be involved in discussions and make informed decisions about their care, as described in NICE's information on making decisions about your care.

Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

Healthcare and social care practitioners should follow our general guidelines for people delivering care:

- Patient experience in adult NHS services
- Babies, children and young people's experience of healthcare
- Disabled children and young people up to 25 with severe complex needs
- Service user experience in adult mental health
- People's experience in adult social care services
- Shared decision making
- Medicines optimisation
- Multimorbidity
- Transition from children’s to adults’ services
- Transition between inpatient hospital settings and community or care home settings for adults with social care needs
- Decision making and mental capacity
- Supporting adult carers
- Advocacy services for adults with health and social care needs
- Home care: delivering personal care and practical support to older people living in their own homes

1.23 Rehabilitation to support education for children and young people

Healthcare, social care and education practitioners should also follow our guidelines about integrated service delivery and organisation for disabled children and young people from birth to 25 with severe complex needs:

- Disabled children and young people up to 25 with severe complex needs

1.23.1 As soon as possible after suspecting or diagnosing a chronic neurological disorder in a child or young person, inform their nursery, school or college.

1.23.2 Provide the nursery, school or college with information about the child’s or young person’s condition and its prognosis, and their rehabilitation needs.

1.23.3 Discuss and agree the support, equipment, adaptations (including environmental adaptations) or adjustments needed to facilitate the child's or young person's rehabilitation and participation in education.

1.23.4 Ensure there is:

- a named healthcare practitioner that education practitioners can contact if they are concerned about the rehabilitation needs of the child or young person
- two-way communication and information sharing between rehabilitation and education practitioners, including during periods of transition, for example, when the child or young person moves to a different school or college, or their teachers change.

1.23.5 Discuss at regular intervals whether the school or college remains right for the child or young person or whether a different education setting is needed.

1.23.6 Regularly review education, health and care plans if they include rehabilitation provision, especially if the person has a chronic neurological disorder that is progressive or fluctuating.

See also the section on goal setting for education, training and work.

For a short explanation of why the committee made this these recommendations and how they might affect practice, see the rationale and impact section on rehabilitation to support education for children and young people.

Full details of the evidence and the committee's discussion are in evidence review K: access to support for education, employment and social participation.

1.24 Rehabilitation and the workplace

These recommendations apply to both paid and voluntary work.

1.24.1 When assessing the person's ability to remain in, or return to, work, take into account:

- their retained skills, strengths and motivations
- whether their rehabilitation needs are likely to increase or decrease.

1.24.2 If the person is unable to remain in, or return to, work, provide support to enable them to leave or change work.

1.24.3 Discuss remaining in, or returning to, work with the person and their employer as early as possible:

- consider undertaking a work capacity evaluation
- help set expectations, and identify and solve any barriers that could prevent the person remaining in, or returning to, work
- collaborate with specific professions in the workplace as needed, for example, occupational health, human resources and legal teams.

1.24.4 When planning return to work see also recommendation 1.16.4 in NICE's guideline on stroke rehabilitation in adults, which is applicable to people with other forms of chronic neurological disorder.

1.24.5 For an employer carrying out a workplace assessment with the person, identify potential barriers to effective working and develop solutions and strategies to overcome them.

1.24.6 Ask the person if and how they want any workplace adjustments (for example, the provision of a support worker) or changes to their role to be explained to their work colleagues and what should remain confidential.

1.24.7 When undertaking vocational rehabilitation, use the most appropriate environment to assess rehabilitation needs and deliver rehabilitation interventions. This may be in the workplace, a hospital clinic, community setting or the person's home.

1.24.8 Check the effectiveness of workplace adjustments and review vocational rehabilitation whenever rehabilitation needs that might impact on work are being reassessed.

1.24.9 The employer should discuss and agree any workplace adjustments for addressing future rehabilitation needs with the person and seek advice from rehabilitation practitioners as needed.

See also the section on goal setting for education, training and work.

See the section on workplace culture and policies in NICE's guideline on workplace health: long-term sickness absence and capability to work for recommendations about vocational support and returning to work.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on rehabilitation and the workplace.

Full details of the evidence and the committee's discussion are in evidence review K: access to support for education, employment and social participation.

1.25 Participating in social and leisure activities

1.25.1 Talk to the person about any barriers preventing them from achieving their social participation goals and work together to overcome these barriers.

1.25.2 Recognise that social participation goals may involve simple, everyday social activities, for example, coffee with a friend or attending play groups.

1.25.3 Help the person to identify social clubs and activities in their local community that might address their social participation goals.

1.25.4 Help with any risk assessments and form filling required to enable participation in social and leisure activities, if needed.

1.25.5 Support the person to explain to organisers of social or leisure clubs or activities any adjustments and adaptations needed to enable them to access the venue or activity

1.25.6 When planning travel, social and leisure activities, take into account toileting needs and availability of accessible public toilets.

1.25.7 Consider online options for social activities if in-person activities are scarce, for example, in rural areas, or travel is challenging.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on participating in social and leisure activities.

Full details of the evidence and the committee's discussion are in evidence review K: access to support for education, employment and social participation.

1.26 Family life and friendships

1.26.1 Offer the person the opportunity to discuss rehabilitation needs and set rehabilitation goals connected with family life and friendships, including parenting and caring relationships

1.26.2 Identify any physical, cognitive, communication, emotional or social barriers to family life and friendships, including parenting and caring relationships as part of rehabilitation assessment, goal setting rehabilitation and planning.

1.26.3 Support the person to maintain and develop parenting and caring relationships by:

- discussing with the person how they are feeling about these relationships in the context of their rehabilitation needs
- address any physical, cognitive, communication, emotional or social barriers to parenting and caring responsibilities
- helping them to access parental support services if needed
- providing targeted rehabilitation interventions, for example, to address specific impairments that impact on caring for another person.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on family life and friendships.

Full details of the evidence and the committee's discussion are in evidence review K: access to support for education, employment and social participation.

1.27 Intimate and sexual relationships, and sex

1.27.1 Provide information about intimate or sexual relationships and sex. This might involve having:

- information clearly displayed in healthcare settings
- sex aids or equipment available to show and discuss.

1.27.2 Offer the person the opportunity to discuss rehabilitation needs and set rehabilitation goals connected with intimate or sexual relationships and sex.

1.27.3 Rehabilitation practitioners should seek advice and support to ensure they are competent and confident discussing rehabilitation needs connected with intimate or sexual relationships and sex.

1.27.4 Rehabilitation practitioners should know when and how to signpost to other services for specialist advice and support about intimate or sexual relationships and sex, for example, psychosexual counselling or continence management.

1.27.5 Rehabilitation practitioners should seek specialist advice, or signpost to a specialist service, if potential safeguarding or consent issues are raised in connection with intimate or sexual relationships and sex.

1.27.6 When discussing, assessing and providing interventions connected with intimate or sexual relationships and sex, take into account the person's gender identity, sexual orientation, and any religious and cultural beliefs.

1.27.7 Identify and address any physical, cognitive, communication, emotional or social barriers to intimate or sexual relationships and sex.

1.27.8 Use appropriate methods to gather initial information about intimate or sexual relationship and sex, for example, by asking the person to complete a questionnaire in their own time.

1.27.9 Ask the person how they might talk about intimacy, sex and sexual functioning with partners and potential partners and provide support with this, for example, advice on sharing relevant personal medical information.

1.27.10 Address rehabilitation needs connected with intimate or sexual relationships and sex by:

- targeted rehabilitation of specific impairments or disabilities
- provision of information
- training for carers or potential sexual partners
- provision of, or signposting to, sex aids or equipment.

1.27.11 Address any barriers within health and social care settings that may restrict rehabilitation in relation to the person’s rehabilitation goals around sex and intimacy, for example, provide door locks where it is safe and appropriate to do so, remove restrictions on internet access, and do not use restrictive clothing and splints.

For a short explanation of why the committee made these recommendations and how they might affect practice, see the rationale and impact section on intimate and sexual relationships, and sex.

Full details of the evidence and the committee’s discussion are in evidence review K: access to support for education, employment and social participation.

Terms used in this guideline

This section defines terms that have been used in a particular way for this guideline. For other definitions see the NICE glossary and the Think Local, Act Personal Care and Support Jargon Buster.

Clinical pathway

Setting out a process of best practice and evidenced rehabilitation options for a person and mapping out the care journey they can expect. A tool to inform decision making and prompts for the involvement (and disinvolvement) of different people and services along the way. Also referred to as care pathways, integrated care pathways, integrated care systems, clinical care pathways, pathways of care or care maps.

Community rehabilitation services

For the purposes of this guidance, community rehabilitation is defined as all rehabilitation interventions and services delivered by rehabilitation practitioners in settings outside of hospital.

Compensatory aids

Compensatory aids are tools or devices designed to help individuals perform tasks more effectively when they face difficulties due to impairments. These aids can include things like smart phone apps, paper diaries, electronic calendars, video games, virtual reality and other computer-based exercises.

Complex case manager

A complex case manager is a named healthcare or social care professional with specialist knowledge in inpatient and community-based rehabilitation and support, including sometimes in education or training support for children and young people. They must be able to commission services, monitor them, and integrate input from various professions. Currently, few NHS professionals have the required specialist knowledge. A complex case manager works with people who have severe, complex, long-term rehabilitation needs and, for example, impaired cognitive or executive function, or serious comorbidities, a learning disability, substance misuse or neurobehavioural symptoms. They provide advice, proactive support and signposting, coordinating care across multiple services including therapists, support workers, clinicians, and community such as transport and housing services. They assess needs, identifies priorities, and create tailored rehabilitation and care plans, acting as advocates and promoting inclusion. Complex case managers review care plans as needed and offer ongoing support as circumstances change. Where assigned, a complex case manager also act as the person’s key worker and key contact.

Errorless and error-based learning

Errorless learning is an instructional method aimed at preventing mistakes during the learning process. This technique involves providing learners with clear, step-by-step guidance and prompts to ensure they successfully complete tasks without errors.

Error-based learning, in contrast to errorless learning, involves allowing learners to make mistakes as part of the learning process, such as trial-and-error. The idea is that errors help learners identify and correct misunderstandings, fostering deeper understanding and long-term retention.

Executive function

A set of skills that underlie the capacity to plan ahead and meet goals, display self-control, follow multiple-step directions even when interrupted, and stay focused despite distractions.

Functional activity

Functional activities are tasks performed as part of one's daily life that require physical or cognitive effort, such as walking, eating, dressing, and engaging in school, work or hobbies. These are important in rehabilitation as they help the person to live independently.

Functional assessment

The evaluation of an individuals’ abilities to perform a specific activity in their day-to-day life. Examples of functional assessments include activities of daily living in the home, memory or cognition skills, psychosocial and behaviour issues, communication.

Holistic rehabilitation needs assessment

Focuses on the person as a whole and not just their condition or injury. Made up of a number of functional assessments and discussions with the person about their priorities and goals. This informs the rehabilitation plan, which is an agreement about the rehabilitation treatments and approaches which will help them to recover, retain or reduce the effects of any deterioration of function and to achieve their rehabilitation goals.

Initial contact

Initial contact is a named healthcare practitioner, such as a nurse, physiotherapist, occupational therapist, psychologist or neurologist, assigned by the responsible clinician following diagnosis or initial treatment for a chronic neurological disorder where potential rehabilitation needs are identified. This contact may be temporary and may also be assigned at hospital discharge, or this person may act as the lead practitioner while holistic assessment is underway. The role could be hospital or community based and provides a link to services, early service delivery and assessment coordination before a rehabilitation plan is finalised and the most appropriate single point of contact is agreed.

Internal and external compensatory strategies

Internal compensatory strategies involve using cognitive techniques or skills to adapt or overcome difficulties. For example, using memory aids like visualisation or creating associations to help recall information.

External compensatory strategies involve using tools or external devices to assist with tasks or challenges. Examples include using calendars, alarms, or speech-to-text software to assist with memory or physical limitations.

Key contact

A key contact may be a named unit, team or person involved in the person's rehabilitation care. This contact can be community or hospital based. The key contact primarily signposts, provides relevant information, and facilitates entry into the service as needs emerge. They seek information and input from others, if they cannot offer advice directly. This contact must remain in place even when the person is not receiving active rehabilitation. If the person is assigned a key worker or a complex case manager, they would also act as the key contact.

Key worker

A key worker is a named healthcare practitioner. This role may change along the pathway, such as after hospital discharge. A key worker can be community or hospital based, working across professional and health and social care boundaries. Key workers support people with impaired cognitive or executive function affecting their ability to self-manage or navigate rehabilitation services, unpredictable or rapidly changing neurological conditions, multiple rehabilitation needs, potential new care access needs, and associated family support needs. They provide signposting, relevant information, and facilitate re-entry into services. They also manage care, coordinate rehabilitation and liaise with other services, such as social care. There are qualified NHS staff currently undertaking this role, but practice varies in whether people are assigned key workers. Where assigned, a key worker also acts as the person’s key contact.

Neurodevelopmental stages

Physical, cognitive, communication, social or behavioural signs of development for infants or children. A set of functional skills or age-specific tasks that most children can do at a certain age range. These stages or milestones provide important information regarding the child’s early development.

Rehabilitation plan

This may be in the form of a rehabilitation prescription. It may also come in different versions such as the rehabilitation passport, which is a patient-held document, and may be a simplified version of the plan. It is carried with the person and also communicated between rehabilitation teams and updated accordingly and used to document information about the condition and rehabilitation treatments in an accessible format.

Rehabilitation practitioners

Any health or social care practitioner contributing to the rehabilitation of a person with chronic neurological disorders at any stage of referral, assessment, delivery, review, follow-up or re-referral.

Rehabilitation practitioners would include but are not restricted to: physiotherapists, occupational therapists, speech and language therapists, dieticians, social workers, mental health workers, consultants/physicians and nurses trained in rehabilitation, disability paediatricians, neuropsychiatrists, orthotists and prosthetists, rehabilitation and therapy assistants, technical instructors, clinical psychologists, creative arts therapists, speciality-specific coordinators, case managers and others performing neuro navigation roles.

Together these practitioners may also form hospital or community based multi-disciplinary teams to deliver holistic assessments and rehabilitation plans and programmes.

Single point of contact

A single point of contact may be a link to a unit, team or person in health or social care involved in the person's rehabilitation (a key contact) or it may be a key worker or a complex case manager. This single point of contact can be community or hospital based. The responsible clinician, the person initiating the assessment, or the inpatient multidisciplinary team, along with community and primary care practitioners, jointly agree on the single point of contact when the rehabilitation plan is finalised. The single point of contact could be a nurse, GP, rehabilitation physician, special educational needs coordinator, allied health professional, family support worker, social worker, case manager, disability paediatrician or speciality-specific coordinator, such as, a neuro navigator or it could be another rehabilitation practitioner.

Depending on the complexity of needs, the single point of contact may signpost, provide information, help navigate rehabilitation services, coordinate rehabilitation, support access to services, and refer to other services as needed. The type of single point of contact will depend on the complexity of needs and the person’s or their family’s ability to self-manage rehabilitation, with a key contact providing the least intensive support and a complex case manager providing the most intensive support. A key contact may not be able to offer direct advice but can seek information from others. A single point of contact must remain even when the person is not receiving rehabilitation, to ensure access to services as needs may emerge. The type of single point of contact needed will vary by person, but also may vary across setting and time.

Skills-based learning

Skills-based learning emphasises the development of specific skills required to perform certain tasks. This type of learning is often hands-on and practical, where learners directly apply and practice the skills needed for a particular job or activity, such as technical skills, communication, or problem-solving.

Specialist neurorehabilitation services

Any rehabilitation service which is specifically tailored to treat and care for people with a chronic neurological disorder, including services for any of the conditions or injuries that can result in neurological impairment or disabling neurological symptoms. This includes specialised rehabilitation services which support patients with complex disability whose rehabilitation needs are beyond the scope of their local rehabilitation services. It would also cover specialist advice, expertise on care or equipment.

Task-based training

A teaching approach where learners engage in activities that replicate real-world tasks that are part of the persons everyday life. The focus is on applying skills to complete specific, realistic tasks rather than focusing on abstract concepts or theoretical knowledge, with the intention of acquiring or reacquiring a skill.

Vestibular problems

Dizziness or problems with balance caused by damage to parts of the inner ear or the brain that process the sensory information involved with controlling balance and eye movements.

Vocational rehabilitation

Focuses on the rehabilitation interventions needed to help people with long-term health conditions or disabilities return to or stay in work, education or training. This may involve adapting working conditions, job roles or retraining.

Working memory

Refers to the cognitive system responsible for temporarily storing and manipulating information necessary for complex tasks such as reasoning, comprehension, and learning. It helps individuals hold and process information in the short term while performing cognitive tasks, like solving maths problems or following multi-step instructions.

Recommendations for research

The guideline committee has made the following recommendations for research.

Key recommendations for research

1 Personal care and activities of daily living in people with a chronic neurological disorder

What is the effectiveness of approaches for improving or maintaining independence in activities of daily living for people with a chronic neurological disorder?

For a short explanation of why the committee made this recommendation for research, see the rationale section on independent living, equipment and environmental adaptations.

Full details of the evidence and the committee’s discussion are in evidence review D: personal care and activities of daily living.

2 Stability, mobility and upper limb function in children and young people with a chronic neurological disorder

What is the effectiveness of interventions and approaches for improving and sustaining stability, mobility and upper limb functioning for people with a chronic neurological disorder?

For a short explanation of why the committee made this recommendation for research, see the rationale section on stability, mobility and limb function.

Full details of the evidence and the committee's discussion are in evidence review E: stability, mobility and upper limb function.

3 Rehabilitation for cognitive function in people with chronic neurological diseases

What is the effectiveness of transcranial direct current stimulation (TDCS) and transcranial magnetic stimulation (TMS) for improving and maintaining cognitive function in people with a chronic neurological disorder?

For a short explanation of why the committee made this recommendation for research, see the rationale section on cognitive function.

Full details of the evidence and the committee's discussion are in evidence review G: rehabilitation for cognitive function.

4 Emotional health and mental wellbeing in children and young people with a chronic neurological disorder

What is the effectiveness and cost-effectiveness of interventions and approaches for improving and sustaining emotional health and mental wellbeing for children and young people with a chronic neurological disorder**?**

For a short explanation of why the committee made this recommendation for research, see the rationale section on emotional health and wellbeing.

Full details of the evidence and the committee's discussion are in evidence review H: emotional health and mental wellbeing.

5 Emotional health and mental wellbeing in adults with a functional neurological disorder

What is the effectiveness and cost effectiveness of interventions and approaches for improving and sustaining emotional health and mental wellbeing for adults with a functional neurological disorder?

For a short explanation of why the committee made this recommendation for research, see the rationale section on emotional health and mental wellbeing.

Full details of the evidence and the committee's discussion are in evidence review H: emotional health and mental wellbeing.

Other recommendations for research

6 Fatigue management in children and young people with a chronic neurological disorder

What is the effectiveness and cost effectiveness of multi modal (that is, combined physical and psychological) rehabilitation for fatigue management for children and young people with a chronic neurological disorder?

For a short explanation of why the committee made this recommendation for research, see the rationale section on fatigue.

Full details of the evidence and the committee's discussion are in evidence review J: fatigue management.

7 Support to access employment in people with a chronic neurological disorder

What is the effectiveness and cost-effectiveness of interventions or approaches for supporting people to enter, remain in, return to or leave employment and volunteering?

For a short explanation of why the committee made this recommendation for research, see the rationale section on rehabilitation and the workplace.

Full details of the evidence and the committee’s discussion are in evidence review M: support to access employment.

8 Access to physical activity in people with a chronic neurological disorder

What is the effectiveness and cost effectiveness of digital applications to support access to physical activity, exercise or sport, for people with a chronic neurological disorder?

For a short explanation of why the committee made this recommendation for research, see the rationale section on physical activity and exercise.

Full details of the evidence and the committee’s discussion are in evidence review O: access to physical activity.

Rationale and impact

These sections briefly explain why the committee made the recommendations and how they might affect practice or services. Recommendations 1.1.1 to 1.14.3 and 1.23.1 to 1.27.11 are based on qualitative evidence.

Service design

Recommendations 1.1.1 to 1.1.5

Why the committee made the recommendations

Evidence showed that holistic rehabilitation requires collaboration between different organisations and services. The committee also agreed that services should be wide-ranging and designed with users and practitioners in mind.

Evidence showed that many people with a chronic neurological disorder do not feel empowered to offer feedback about their service experiences. The committee agreed that this could be addressed by encouraging people to share their experiences and using this feedback to inform and improve service design.

Evidence found that rehabilitation is often only considered when symptoms start to affect functioning and is only provided in the short term for specific symptoms, despite people with a chronic neurological disorder saying they needed long-term follow-up or regular reviews. The committee agreed that designing services with lifelong care and support in mind, from initial presentation or diagnosis, will enable more timely access to services as future needs will be better anticipated. Evidence highlighted that an efficient model of rehabilitation should encompass healthcare, social care and the third sector. The committee recommended that services operate across all health and care settings, including both specialist neurorehabilitation and general rehabilitation services.

Evidence showed that people with a chronic neurological disorder tend to need periods of intensive treatment followed by periods of less intensive support. Furthermore, people reported finding it helpful when rehabilitation could be undertaken at home or in community setting as well as clinical settings.

The committee agreed it was important that there were clear lines of responsibility for coordination of clinical pathways in each area and an accountable lead for both children’s and adults’ service provision.

How the recommendations might affect practice

Some rehabilitation services already gather feedback from people with a chronic neurological disorder to improve service design and clinical pathways. These initiatives are generally low cost, often using electronic questionnaires.

Designing rehabilitation services with flexible, integrated clinical pathways across different providers may require additional resources and may put pressure on existing services. However, the need for extra resources can largely be achieved by using existing resources differently.

Designing rehabilitation services and pathways with lifelong support and care in mind may enable timelier access to assessment and care, which may reduce reliance on crisis care.

Return to recommendations

Commissioning rehabilitation services and service specifications

Recommendations 1.2.1 and 1.2.2

Why the committee made the recommendations

The committee acknowledged that rehabilitation services can be challenging to navigate. They recommended a model of care whereby everyone with a chronic neurological disorder is assigned a key contact, key worker or complex case manager depending on the complexity of their needs. Such a model of care would improve outcomes by ensuring timely access to appropriate care.

Evidence showed that commissioners should focus on a holistic approach to rehabilitation. The committee set out the minimum service specification required to do this.

How the recommendations might affect practice

The roles of key contact and key worker could be undertaken by existing practitioners, avoiding the need to create new roles. However, there is a lack of complex case managers and providing these roles, even for the minority of people with the most complex needs, is likely to require significant resources.

The services listed in the minimum service specification already exist, but availability varies across the country. Additional resources may be needed to establish services where they do not exist. Many services currently operate in isolation, so integrating and joining these up may require additional resources.

Implementing the recommendations may enable timelier access to assessment and care, which may reduce reliance on crisis care, potentially offsetting any additional costs.

Return to recommendations

Building local capacity and expertise

Recommendations 1.3.1 to 1.3.7

Why the committee made the recommendations

Evidence highlighted that poor communication between rehabilitation services leads to poor continuity of care, particularly when someone is moving between services. The committee agreed that collaboration between services starts with commissioning bodies from different sectors making decisions together.

The committee recognised that practitioners delivering mental health services have varying degrees of experience of working with people with a chronic neurological disorder. They highlighted that interventions often need adapting for these groups of people. Local service level agreements should aim to increase the availability of mental health practitioners who are trained to work with people with a chronic neurological disorder. This should be done by developing workforce skills and communication channels between mental health practitioners specialising in neurorehabilitation and generalist mental health services.

Evidence showed increasing levels of knowledge of chronic neurological disorders within primary care settings can help improve identification of rehabilitation needs and increase suitable referrals. It also showed that healthcare practitioners often focus on physical and visible symptoms, which can act as a barrier to accessing appropriate rehabilitation services. Some practitioners have prejudged ideas about how certain disorders and injuries will respond to rehabilitation treatments. This can result in health inequalities.

Evidence showed that the expense of procuring treatments was a common barrier to provision. The committee noted that although assistance is available to providers for some of the more costly treatments or services, these are often not publicised or widely known about. They agreed that rehabilitation practitioners need to know how to commission high-cost equipment and services.

Evidence showed people were prevented from accessing appropriate services because of a lack of availability of specialist centres and services. Furthermore, it found that increasing access to specialist knowledge and skills led to provision of a wider variety of rehabilitation services. And increasing the capacity of rehabilitation services improved both identification of rehabilitation needs and access to appropriate services. The committee was aware of the resource impact of increasing specialist centres and so focused instead on increasing access to specialist knowledge within existing services.

Evidence showed that people had different preferences about group settings for facilitating social participation. While some people like group settings, others do not.

How the recommendations might affect practice

Greater collaboration between commissioning bodies may involve increased information sharing, joint working, and service level agreements. Establishing frameworks to support this may have some resource implications, but these are unlikely to be significant.

There is a lack of mental health services for people with a chronic neurological disorder, and general mental health services are currently not well-equipped to meet this need. Additional funding for staff training and additional staff may be required.

More resources may be needed to ensure GPs and other primary care practitioners can support people with a chronic neurological disorder. Sharing expertise from specialist centres and keeping up-to-date information on local services could achieve this without requiring formal training. This approach is already in place in some areas and is not expected to require significant additional resources.

NHS England already funds high-cost specialist equipment and services. Raising awareness of this among health and social care practitioners will only speed up access.

There is variation in the availability of social and leisure group activities for people with a chronic neurological disorder. Additional resources may be needed to establish these where they do not exist, but use of online options could mitigate the potential resource impact.

Return to recommendations

Providing responsive services

Recommendations 1.4.1 to 1.4.4

Why the committee made the recommendations

Evidence showed that poor coordination of rehabilitation services for people with a chronic neurological disorder, particularly when transferring between services, prevented continuity of care and sometimes led to poor physical and cognitive functioning. The committee recognised that poor coordination of services is often due to a lack of communication and collaboration between services, including those outside the NHS.

Evidence showed that people with a chronic neurological disorder preferred, and benefited from, ongoing access but low intensity contact with rehabilitation services even when their needs were well managed. They also appreciated clear methods for self-referral and to be able to request a review of their needs, if and when necessary. The committee agreed that a reliable and simple process should be in place for people to re-access services, aiding timely intervention and reducing the chances of further deterioration of function.

Evidence showed that poor communication and coordination across rehabilitation services often meant rehabilitation needs were not shared appropriately. The committee agreed that findings from assessments should be shared.

The committee also recognised that providing responsive services may mean that certain services face short-term, above-average demand. This potential need for increased capacity and expertise should be taken into account when planning resources.

How the recommendations might affect practice

Most rehabilitation services collaborate to address the needs of people with a chronic neurological disorder, but practices vary. Greater collaboration may involve increased information sharing, joint working and service level agreements. Establishing frameworks to support these may have some resource implications, but these are unlikely to be significant.

Although referral procedures are in place to allow access to rehabilitation services, delays can occur because of capacity issues, time taken to assess needs or lack of awareness among practitioners of the availability of services. Ensuring ongoing access, re-access and self-referral could increase pressure on existing services. However, it will enable timelier access to assessment and care, which may reduce reliance on crisis care, potentially offsetting any additional costs. It may also reduce the number of people contacting their GPs in order to access care.

Return to recommendations

Early discussion about prognosis and rehabilitation

Recommendations 1.5.1 to 1.5.4

Why the committee made the recommendations

Evidence showed that early identification of rehabilitation needs led to timely referral, enabling access to interventions or planning for future care.

Discussions about prognoses soon after diagnosis or injury was also found to support people in monitoring and planning for their rehabilitation needs. The committee acknowledged that not everyone may be ready for these conversations. If this is the case, the person’s preferences should be respected, with ongoing opportunities offered for discussion as needed.

Evidence showed the importance of a single contact point for rehabilitation. The committee agreed that it was important for the responsible clinician to give the person a contact for rehabilitation, even if rehabilitation was not being started at that point. The committee agreed that the details of this initial contact should be shared with the person and their GP at the earliest opportunity to ensure continuity of communication.

How the recommendations might affect practice

Starting assessments for rehabilitation before a diagnosis is confirmed may increase demand for initial assessments and put pressure on existing services. However, early needs assessment is crucial as some diagnoses can take years to establish.

Some people are being provided with a contact for rehabilitation at an early stage, such as a responsible clinician or a link to a rehabilitation unit or team, but practices vary. Consistently implementing this may require additional resources, mainly more staff time.

Implementing the recommendations may enable timelier access to assessment and care, which may reduce reliance on crisis care, potentially offsetting any additional costs.

Return to recommendations

Hospital discharge

Recommendations 1.6.1 to 1.6.3

Why the committee made the recommendations

Evidence showed that people with a chronic neurological disorder need to be given a contact for rehabilitation when they are discharged from hospital. The committee agreed that a contact for rehabilitation was needed even before rehabilitation had begun because for long-term conditions rehabilitation can be anticipated as a requirement at some point in the future.

For cases where either rehabilitation assessment or treatment has begun prior to discharge, an inpatient multidisciplinary team member might serve as the rehabilitation contact during hospital stay. However, as the person is discharged home it is important to agree who is best placed to take on this role before a rehabilitation plan is agreed and a more permanent single point of contact is appointed (see chapter 1.11). The committee therefore set out a number of practitioner roles who could act as an initial point of contact post discharge.

Evidence showed that poor coordination during discharge led to delays and unmet needs at home. The committee agreed that delays in arranging equipment and environmental adaptations often extend inpatient stays unnecessarily.

How the recommendations might affect practice

It is usual practice for someone to have a hospital-based clinical contact at discharge or immediately following discharge for follow-up.

Using existing roles to act as the initial contact for rehabilitation avoids the need for creating new roles. This has the potential to increase workload for the person involved. However, it may enable timelier access to assessment and care, which may reduce reliance on crisis care, potentially offsetting any additional costs.

NHS England already provides pathways and funding for equipment, assistive technology and environmental adaptations, but there are delays in assessing needs and providing adaptations to address these needs, leading to delays in discharge. These recommendations may enable earlier access to essential support, but since funding is already available, no additional resources are expected. This would also avoid costly discharge delays for the NHS.

Return to recommendations

When to undertake, or make a referral for, holistic rehabilitation needs assessment

Recommendations 1.7.1 to 1.7.3

Why the committee made the recommendations

Evidence showed that starting holistic rehabilitation needs assessment as soon as a chronic neurological disorder is diagnosed or suspected enables timely access to interventions, and may slow symptom progression.

Healthcare practitioners were often found to prioritise physical functioning, overlooking less visible impairments such as social, psychological, emotional, cognitive and communicative. This can delay access to appropriate rehabilitation. The committee agreed that non-physical needs were as important to assess as physical needs.

The committee noted that people with a chronic neurological disorder often experience long periods of stability when rehabilitation assessments may not be necessary at every appointment. However, people should be informed of how to request an assessment if their needs change, for example because of worsening symptoms or altered circumstances.

How the recommendations might affect practice

Starting assessments for rehabilitation before a diagnosis is confirmed may increase demand for initial assessments and put pressure on existing services. However, early needs assessment is crucial as some diagnoses can take years to establish. It may enable timelier access to assessment and care, which may reduce reliance on crisis care, potentially offsetting any additional costs.

Return to recommendations

Holistic rehabilitation needs assessment

Recommendations 1.8.1 to 1.8.21

Why the committee made the recommendations

Support and advocacy for making decisions during rehabilitation

Evidence indicated that involving the person's support network, such as carers, family or formally appointed advocates, is often critical in helping ensure they get access to appropriate rehabilitation services. The committee agreed that many people with a chronic neurological disorder need the support and advocacy of others to help them make decisions about their care and treatment and this support needs to put in place before holistic rehabilitation needs assessment is underway.

Initiating holistic rehabilitation needs assessment and who to involve

The committee agreed that assessment for rehabilitation should be holistic, considering all aspects of a person's functioning. They noted that effective rehabilitation planning requires a comprehensive understanding of the person's rehabilitation needs, as addressing isolated symptoms, such as gait difficulties, without considering others, like fatigue or executive dysfunction, may negatively impact adherence to the rehabilitation plan.

The committee acknowledged that contact with rehabilitation services often begins with a referral for a very specific assessment relating to a single area of impairment, such as speech and language, and it is only at this point that the practitioner becomes aware of other areas of impairment or symptoms that also need addressing. The committee agreed that holistic needs assessment should be the default position. They discussed and agreed the criteria for deciding when holistic assessment is not needed.

Coordinating holistic rehabilitation needs assessment across multiple specialties can be challenging. The committee agreed that the person initiating the assessment should oversee the initial stages and contact relevant health and social care practitioners. This person and the practitioners they are in contact with should then agree the most suitable person to lead the assessment.

Evidence showed that those close to people with a chronic neurological disorder are often best placed to observe changes in cognitive functioning, physical functioning and emotional well-being and to support rehabilitation activities. The committee noted that these people can play a key role in the delivery of many rehabilitation interventions but that practitioners should not make assumptions either about who the person wishes to involve or whether those people are willing to be involved.

The committee recognised that rehabilitation should not be delayed for needs that have already been identified, while they are undergoing or waiting for assessments for other potential needs. This is to ensure timely rehabilitation planning and delivery.

What to cover

Evidence highlighted that rehabilitation needs assessment for people with a chronic neurological disorder requires an individualised approach. The committee discussed and agreed the wide range of topics and issues that should be discussed with the person when undertaking holistic rehabilitation needs assessment.

Evidence highlighted a bias towards assessment of biomedical functioning, with less importance given to assessment of emotional wellbeing and mental health, and cognitive impairments. The committee recognised that co-morbidities, such as depression, can prevent people from engaging in rehabilitation. The committee noted that such symptoms or impairments are often identified by chance during unrelated discussions. Equally, they noted that conversations about challenges in the person’s life may uncover difficulties and their underlying causes and identify rehabilitation needs.

Evidence showed the importance of providing information, advice and training for people with a chronic neurological disorder early in the rehabilitation process to support decision-making.

The committee agreed that it was important to identify interventions to help the person prepare for future changes to impairment and functioning.

The committee noted the importance of assessing all factors impacting functional capability, symptoms and impairments as part of holistic rehabilitation needs assessment. They noted that multiple impairments often coexist, making thorough evaluation critical in identifying and addressing unmet needs.

The committee agreed that holistic needs assessments should recognise variations in the person's functioning across different real-life environments, such as managing tasks at home versus a busy town centre. They also noted that abilities and needs may fluctuate throughout the day, from day to day, or over time.

The committee noted that holistic assessments should take into account what matters to the person, including in relation to education, work, social and leisure activities and relationships.

The committee noted that people with memory or learning difficulties are often excluded from rehabilitation. They agreed that reasonable adjustments should be made to prevent this from happening.

Related assessments

Some adults may qualify for NHS continuing healthcare, which funds rehabilitation and reduces physical, emotional and financial burdens on people with a chronic neurological disorder. The committee acknowledged that multidisciplinary teams are needed to complete the NHS continuing healthcare checklist. For children and young people, rehabilitation support may be provided through an education, health, and care (EHC) plan arranged by the local authority.

The committee acknowledged that social care needs for people with a chronic neurological disorder are often not addressed by the healthcare system, which can affect rehabilitation.

How the recommendations might affect practice

Capacity may need to increase to meet the demand for holistic rehabilitation needs assessment as the default process. More resources may be needed to ensure staff are skilled to undertake assessments. Additional resources may be required for managing referrals, scheduling and IT systems for communication across health and social care providers in relation to assessments.

Additional staff time may be needed for conducting initial assessments and reviewing needs. However, it may enable timelier access to assessment and care, which may reduce reliance on crisis care and paid carers, potentially offsetting any additional costs. It may also increase the chances of people returning to work or participating in vocational or social activities, thus offering broader social and economic benefits.

Needs assessments for people with a poor prognosis may result in interventions to optimise or maintain functioning, potentially reducing the need for paid carers and positively impacting mental health and emotional wellbeing, thus reducing related NHS costs.

NHS England already provides pathways and funding for services like NHS continuing healthcare, and education, health, and care (EHC) plans are arranged by local authorities.

Return to recommendations

Goal setting

Recommendations 1.9.1 to 1.9.12

Why the committee made the recommendations

Evidence highlighted the need for rehabilitation practitioners to provide information on the purpose and process of goal setting in rehabilitation. This improves engagement in goal setting.

People with a chronic neurological disorder, their families, and practitioners reported reduced motivation when goals were perceived as too difficult or unrealistic. Therefore, long-term goals should be broken into smaller, short-term steps. This helps people see how their goals and treatment relate to their long-term recovery or condition management.

Evidence showed that children with communication difficulties had problems participating in goal setting as they were not easily understood by practitioners. This resulted in parents delaying their child's involvement in goal setting until they were older. Using age-specific approaches to goal setting, such as simplified language, helps involve children and young people in a more meaningful way.

Evidence highlighted that goal setting is more realistic when discussions are honest about the potential for goals not to be achieved. The committee acknowledged that honesty fosters trust and rapport but should be balanced with maintaining motivation.

Evidence indicated that healthcare practitioners require time during consultations to set goals and make rehabilitation plans for people with a chronic neurological disorder. Time is needed to build rapport with the person and their family, support them through emotional distress and enable full engagement in rehabilitation planning.

Evidence showed that the need to review goals evolves over time, with frequent reviews and a focus on physical rehabilitation early on, shifting to less frequent reviews and a focus on longer-term, psychological goals later on.

Evidence highlighted that engagement during goal setting and rehabilitation planning varied widely for children and young people with a chronic neurological disorder. Children were more motivated when goals were enjoyable, practical and relevant to their growth and developmental stage.

For education, training and work

Evidence highlighted that having realistic rehabilitation goals in relation to work improved engagement. The committee agreed these principles applied to goals about training and education.

How the recommendations might affect practice

The recommendations on goal setting outline good practice. More resources may be needed to implement these where current practices are sub-optimal. For example, more practitioner time may be required to ensure effective goal setting.

Appropriate goal setting can improve engagement and participation in rehabilitation, enhancing health and wellbeing, and potentially saving costs for the NHS.

Inadequate goal setting may lead to spending on inappropriate or low-priority interventions, negatively impacting engagement with rehabilitation and causing deterioration. This may increase the need for expensive interventions, crisis care and paid carers, potentially incurring substantial costs to the NHS.

Return to recommendations

Agreeing and delivering a coordinated rehabilitation plan

Recommendations 1.10.1 to 1.10.8

Why the committee made the recommendations

Evidence showed that appointments for rehabilitation planning were often biased towards biomedical functioning rather than taking a holistic approach. It found that people with a chronic neurological disorder wanted a rehabilitation plan that reflected their needs and goals. Evidence also highlighted that rehabilitation planning and delivery should involve family members or other people important to the person to achieve the best possible outcomes.

People with a chronic neurological disorder were found to be dissatisfied with the short timeframe of many courses of rehabilitation, which were often designed to address specific symptoms or impairments. People with mild or moderate symptoms often had to wait for symptoms to progress before being offered rehabilitation. The committee also noted that people can feel overwhelmed by the number of different interventions being started at once and this can lead to disengagement and poorer outcomes. Therefore, the committee recommended that the timing, intensity and frequency of different interventions, and how interventions relate and interact, should be central when planning interventions over both short and long timeframes.

Evidence showed that people can be prevented from accessing appropriate rehabilitation services when healthcare practitioners do not believe rehabilitation will be effective for them. The committee agreed that some healthcare practitioners have pre-conceived ideas of what disorders and symptoms may not benefit from rehabilitation, which could stem from the belief that rehabilitation is for treating disabilities rather than optimising or maintaining functioning.

Some people with a chronic neurological disorder were found to prefer rehabilitation to be delivered in a combination of home, community and clinical settings. The committee agreed that the most appropriate setting was usually the one most aligned to the person's goals and that it was important to take their preferences into account.

Evidence showed that collaboration between healthcare and education services helped to increase efficiency of education support during rehabilitation. It also showed that involving employers in rehabilitation planning provided opportunities to discuss and manage expectations about delivering rehabilitation interventions within the workplace.

Education support plans for adults with a chronic neurological disorder may not be reviewed. This means that changing needs are not identified, which can place stress on adult students.

Evidence showed that collaboration between practitioners helped to ensure that interventions were appropriate. It also showed that poor communication and coordination led to practitioners not having the correct and up-to-date information when treating a person and so providing ineffective or untimely treatments.

Evidence showed that planning is more realistic when conversations are honest. The committee agreed that discussions should include possible rehabilitation interventions for the future and decisions on when to stop current interventions.

How the recommendations might affect practice

Currently, generic rehabilitation plans are often offered. Individualising these plans based on holistic rehabilitation assessments and involving the person's family may require additional staff time. Early rehabilitation is not commonly provided and offering it to all people with a chronic neurological disorder, including those with poor prognoses, may increase access to interventions.

However, effective rehabilitation plans may help maintain independence, reduce the need for paid carers, and positively impact mental health, thus reducing overall NHS costs. Some resources may be needed to support rehabilitation services to engage with employment and education sectors. However, it may increase the chances of people returning to work or participating in vocational or social activities, thus offering broader social and economic benefits.

Return to recommendations

Assigning a single point of contact and assessing the person's ability to coordinate their own care

Recommendations 1.11.1 to 1.11.6

Why the committee made the recommendations

Evidence showed that a single point of contact can help people with a chronic neurological disorder to coordinate their rehabilitation and provide information on accessing different services. It also showed that people want assistance with navigating the rehabilitation system and to build rapport and long-term relationships with rehabilitation providers. The committee agreed that people and their families and carers do not always have the knowledge needed to navigate services, particularly at the beginning of rehabilitation. Therefore, the committee recommended that each person is provided with a single point of contact to support them.

The committee recommended assessing the person's ability to self-manage their rehabilitation to determine the most appropriate type of single point of contact, and reviewing this if their needs change. They agreed that only people who were unable to coordinate their own rehabilitation should receive more intensive levels of support. They recognised that the level of support required may change during rehabilitation and extra support may only be needed on a temporary basis.

The committee also agreed that practitioners should think about the requirements of the role as well as the needs of the person before agreeing on a single point of contact.

They also discussed and agreed the criteria for assigning a key worker and complex case manager.

The committee acknowledged that complex case management can be expensive. Given the lack of effectiveness evidence, economic analysis aimed to estimate the required health benefits of complex case management for it to be effective. This analysis included a US study that showed cost reductions because of reduced A&E visits and hospital admissions. Cost effectiveness estimates were more likely to be within the range that NICE considers acceptable when the additional cost savings from reduced visits to A&E and hospital admissions were taken into account. Furthermore, the committee agreed that the findings of the analysis were consistent with their experience. In their opinion, and given current pressures on the NHS, the use of complex case managers may relieve strain on hospital resources and could therefore prove invaluable.

How the recommendations might affect practice

The roles of key contact and key worker could be undertaken by existing practitioners, avoiding the need to create new roles. However, there is a lack of complex case managers and providing these roles, even for the minority of people with the most complex needs, is likely to require significant resources.

Implementing the recommendations may enable timelier access to assessment and care, which may reduce reliance on crisis care, potentially offsetting any additional costs. It may also reduce the number of people contacting their GPs in order to access care. Assigning a complex case manager, if needed, may provide other benefits such as reducing prolonged stays in inpatient neurobehavioural units or residential care.

Return to recommendations

After the rehabilitation plan

Recommendations 1.12.1 to 1.12.5

Why the committee made the recommendations

If the person’s single point of contact is going changing once rehabilitation has ended, this should be communicated.

The committee discussed and agreed the factors that should be taken into account when deciding whether a follow-up appointment will be needed and who should be involved. Making a decision on who will be involved will allow for good communication and coordination.

The committee agreed that the rehabilitation needs of children and young people will change as they grow and develop and therefore follow-up should be planned around key changes.

They also agreed that information about accessing equipment, technology and advice should be provided before rehabilitation ends.

How the recommendations might affect practice

These recommendations should be standard practice for most services, but there may be resource implications for services where practices are sub-optimal. For example, additional staff time might be needed to agree and carry out follow-up appointments and ensure access to necessary equipment, technology and advice.

Re-access and self-referral are major challenges to people with a chronic neurological disorder and healthcare practitioners. Ensuring people know their single point of contact and how to get in touch if their symptoms or impairments change may enable timelier access to assessment and care, which may reduce reliance on crisis care, potentially offsetting any additional costs. It may also reduce the number of people contacting their GPs in order to access care.

Return to recommendations

Information, advice and learning as part of rehabilitation

Recommendations 1.13.1 to 1.13.6

Why the committee made the recommendations

Evidence showed that access to rehabilitation was reduced when the person, and their family or carers, had limited understanding of their condition. Access to rehabilitation services, social care and other support services were reduced when the person did not receive personalised information. The committee discussed and agreed the key areas that should be covered by personalised information.

Evidence showed that insufficient financial support to access equipment, such as wheelchairs, and transport hindered social participation. It also highlighted that applying for government support is often bureaucratic and confusing, particularly for people with cognitive symptoms. The committee noted that while funding exists, it is poorly advertised, and the applications processes are difficult to navigate.

The committee highlighted the statutory requirement for local authorities to assess care and support needs for both paediatric and adult populations. However, as assessments must be requested and are not automatically offered, many people with a chronic neurological disorder and their families are unaware of this right. The committee agreed that advice should be given about this.

Evidence highlighted that information should be accessible and timely, and is particularly beneficial during service transitions. It also showed people with a chronic neurological disorder wanted detailed information on available therapies and equipment. The committee agreed that information should be offered as and when the person's needs change.

The committee agreed it was important to consider opportunities to deliver different elements of the person's rehabilitation plan at the same time.

The committee discussed the challenges for people disclosing information about their condition and rehabilitation needs in the community and socially. They noted the importance of providing support with this.

How the recommendations might affect practice

Most services should already provide information that is tailored to individual needs. However, the committee noted variations in practice. Where this is not done, additional resources may be needed, mainly staff time to develop or collate relevant resources and direct them to relevant services.

Return to recommendations

Pain management

Recommendations 1.14.1 to 1.14.3

Why the committee made the recommendations

The committee agreed that identifying pain in people with a chronic neurological disorder is important because managing pain is fundamental to enabling the person to engage in rehabilitation. So, they recommended that healthcare practitioners ask about pain as part of holistic rehabilitation needs assessment.

The committee highlighted that quite often people with a chronic neurological disorder may persevere with pain or be prescribed analgesia that is ineffective. They recognised that healthcare practitioners can support people with a chronic neurological disorder to understand and manage their pain and so made a recommendation about this.

The committee agreed that pain has a negative impact on physical functioning and emotional wellbeing, which can decrease potential benefits of rehabilitation interventions. They recommended that pain management should be discussed alongside rehabilitation goals and plans. They also discussed and agreed a list of interventions that could contribute positively to pain management and quality of life, recognising that both physical and psychological interventions can help.

How the recommendations might affect practice

Pain management is already integral to rehabilitation. Including pain assessment in holistic needs assessments and consistently considering it throughout the rehabilitation journey may identify more people needing pain management. However, many existing rehabilitation interventions can also reduce pain or improve pain management, so no significant increase in resource use is anticipated.

Return to recommendations

Fatigue

Recommendations 1.15.1 to 1.15.7

Why the committee made the recommendations

Assessment

The committee recognised the impact of fatigue on health and wellbeing, and was aware that rehabilitation practitioners often overlook it. Based on their experience, they made recommendations on when and how to assess fatigue. This should include taking account of fluctuations in fatigue.

Some people with a chronic neurological disorder may have difficulty expressing that they have fatigue and family and carers are therefore critical in highlighting the impact fatigue is having, so that the correct interventions and support can be put in place.

The committee highlighted several treatable factors that can contribute to fatigue other than the person’s chronic neurological disorder. They agreed it was important to check for these so that the correct treatment can be sought.

Interventions

Evidence on the effectiveness of specific combinations of physical activity and psychological interventions for managing fatigue was inconsistent. However, it showed energy-conservation strategies, cognitive behavioural therapy and appropriate physical activity (in terms of frequency, intensity and duration) can reduce fatigue. Therefore, the committee agreed these interventions could form part of fatigue management. They also recognised that physical activity has longer-term benefits in terms of general health.

The committee discussed the difference between energy-conservation strategies for children and young people as opposed to adults. For adults this often involves helping them to choose between competing priorities and balancing between activities, whereas for children and young people it is more about planning breaks and opting out of certain activities.

There was a lack of evidence on interventions for fatigue management in children and young people. Therefore, the committee made a recommendation for research on fatigue management in children and young people with a chronic neurological disorder, to inform future recommendations.

How the recommendations might affect practice

Many people with a chronic neurological disorder report fatigue, but it is often overlooked by healthcare practitioners. Implementing these recommendations may require additional resources. However, fatigue management typically involves low-cost interventions like discussions and advice on pacing and energy conservation strategies, which are not expected to have a significant resource impact.

Return to recommendations

Physical activity and exercise

Recommendations 1.16.1 to 1.16.5

Why the committee made the recommendations

The committee agreed that physical activity programmes are important for optimising muscle strength and physical functioning, but they need to be of the correct frequency, duration and intensity. This is often overlooked.

Problems with executive function, fatigue and pain can create significant barriers to physical activity and so should be taken into account when developing physical activity programmes. The committee noted that supervised exercise, provided on an individual or group basis by an occupational therapist, physiotherapist or coach, can increase engagement.

The committee recognised that other activities could help with the person’s general physical health. Having a discussion with them to identify activities they enjoy, including activities they can do independently, such as walking, can help ensure they stay physically active in the long term.

Evidence showed that behaviour change interventions, delivered separately or alongside the person’s physical activity programme, are effective in supporting sustained engagement in physical activity. One study also showed that a physical activity programme with a behaviour change component was cost effective. The committee also agreed that a person’s family play an important role in encouraging physical activity, especially for a child or young person.

There was no evidence comparing different types of behaviour change interventions and the committee was not confident in recommending a specific intervention. Instead, they agreed to recommend interventions based on cognitive behavioural therapy, self-determination theory, social context theory, motivational interviewing or coaching techniques as they use similar techniques to encourage behaviour change and showed similar results.

The committee discussed barriers that could prevent people from achieving their physical activity goals. They agreed that it is important to talk to the person to identify barriers and offer appropriate support.

The committee discussed the use of digital applications, such as the NHS Couch to 5K app, to promote physical activity. Although no evidence was identified, the committee noted the economic viability and growing popularity of these self-help tools. They made a recommendation for research on the effectiveness of digital applications to support people with a chronic neurological disorder to undertake physical activity.

How the recommendations might affect practice

Physical activity programmes are often not optimised in frequency, duration, and intensity. Therefore, there may be potential resource implications where practices are sub-optimal. Often physical activity programmes may involve suggesting simple activities like walking, yoga or directing to existing self-help resources.

Engagement is a barrier and the availability of behavioural change interventions to sustain engagement with physical activity varies. Where such interventions are not available, introducing them may have a significant initial resource impact in terms of staff training to deliver these interventions. However, there will not be significant ongoing costs in delivering behaviour change interventions, with all recommended options having comparable costs. Any additional costs are very likely to be offset by improved health outcomes, such as reduced fatigue, and improved cardiovascular, general physical and mental health, because of increased participation in physical activity.

Return to recommendations

Stability, mobility and limb function

Recommendations 1.17.1 to 1.17.14

Why the committee made the recommendations

Evidence on standardised exercises for improving and sustaining stability, mobility and upper limb functioning showed there were some benefits to these types of exercises. However, the committee noted that specific and targeted training and exercises are more effective in addressing the diverse needs of people with a chronic neurological disorder. Based on their experience and expertise, they provided a list of interventions that can be targeted to the person’s needs around stability, mobility and both upper and lower limb function. The committee included 2 types of interventions for addressing needs around self-care and activities of daily living, functional activity and wheelchair skills training, given the overlap between these interventions and interventions for stability, mobility and limb function.

The committee agreed that splints and orthoses are used as standard for stability, mobility and upper and lower limb function in people with a chronic neurological disorder.

Evidence on the use of gaming modalities and virtual reality to enhance exercises for stability, mobility and limb functioning showed they improved engagement with rehabilitation. The committee agreed that engagement is a vital element of rehabilitation, and gaming modalities and virtual reality can help with this, especially for children and young people.

The committee emphasised the importance of agreeing exercises and training that the person can do independently (or with the help of family or carers) and as part of their day-to-day activities, including once supervision of activities has come to an end.

The committee agreed that serial and removable casting can restore or help maintain limb function and can prevent pain and joint misalignment. It is particularly useful for children and young people, because it can be adapted to growing limbs.

No evidence was identified for 24-hour postural management strategies. The committee used their experience and expertise to make recommendations in this area, stressing that it is an important aspect of care.

There was a lack of evidence on interventions for under 18s, so the committee made a recommendation for research on interventions to improve and sustain stability, mobility and upper limb functioning for children and young people with a chronic neurological disorder.

Treadmill gait training

Evidence on effectiveness of treadmill gait training in improving gait and balance outcomes aligned with the committee’s knowledge and experience, particularly in terms of increasing exercise capacity leading to improvement in other areas of rehabilitation linked to motivation, engagement and long-term participation. The committee also noted it can promote long-term participation in physical activity.

Evidence on different frequencies of treadmill training showed that high-frequency training produced worse outcomes than low and intermediate frequency in people with Parkinson’s disease. The committee agreed this could be extrapolated to other types of progressive neurological disease and so recommended low- and intermediate-frequency treadmill training for this population.

Evidence showed some benefit of using robot-assisted treadmill gait training. Although the committee argued that this intervention can be effective, they acknowledged that the ability to offer it is likely to be influenced by the availability of appropriate equipment.

The committee recognised that exercise capacity will decrease quickly once treadmill gait training has stopped. Therefore, they recommended support to prevent this from happening.

Electrical stimulation

The committee used their knowledge and experience to make recommendations on electrical stimulation.

They noted that neuromuscular electrical stimulation can add muscle strength for both upper and lower limbs for people with a peripheral or central nerve disorder.

The committee also noted that functional electrical stimulation can optimise the timing and strength of muscle contractions during walking for people with muscle weakness caused by lower motor neuron lesions.

Interventions for vestibular problems

The committee used their knowledge and experience to make recommendations on vestibular exercises and procedures. They noted that balance problems can be a result of central or peripheral vestibular changes, particularly in people with acquired brain injuries or spinal cord injuries.

How the recommendations might affect practice

Most of the recommended interventions for stability, mobility and limb function problems are standard practice and implementing them is not expected to have a resource impact.

Sustaining engagement and timely access to rehabilitation is challenging. Gaming modalities and virtual reality may help with this. Virtual reality equipment costs around £2,000 but can be reused for multiple patients. Therapists can monitor several patients simultaneously and there is potential to replace costly traditional machines. Practice varies, with some centres already equipped. Overall, this recommendation is not expected to significantly impact resources.

Robotics have high initial costs but can save professional time, allowing greater training intensity and potentially better outcomes due to the dose-response relationship. They enable long-term training and are likely to be cost effective, especially given the staff shortage for delivering and supervising rehabilitation. However, robotic use and hydrotherapy is recommended only where equipment and facilities are available, and no significant resource use is anticipated.

Not all devices for functional electrical stimulation and neuromuscular electrical stimulation are NHS-funded. Some people buy the devices themselves or use Personal Independence Payment funding. The recommendations on electrical stimulation are not expected to result in a significant resource impact although some community settings may need to buy additional devices.

Return to recommendations

Emotional health and mental wellbeing

Recommendations 1.18.1 to 1.18.16

Why the committee made the recommendations

Principles of assessment, referral and intervention selection

The committee agreed that the emotional health and mental wellbeing of people with a chronic neurological disorder are often overlooked by rehabilitation practitioners but are important aspects of rehabilitation, especially at key life stages when a person's need for support may be greater.

They identified a couple of issues that need to be recognised when assessing emotional health and mental wellbeing:

- neurological injury can cause emotional lability and should not be confused with the person's psychological response to their condition
- unmet needs in other areas of rehabilitation may cause problems with emotional health and mental wellbeing.

They also agreed that if emotional lability is suspected, it is important to refer for appropriate management and to take account of it when planning rehabilitation.

The committee discussed how having a chronic neurological disorder can affect self-identity, noting that while some people experience minimal change, others feel profoundly different. This impact is especially relevant for people with spinal cord injuries where wheelchair use affects their interactions with other people and the world. The committee agreed the importance of allowing adequate time and support for the person to adjust to, and accept, their condition, including delaying treatment, if needed.

Agreeing goals and interventions for emotional health and mental wellbeing within the context of other rehabilitation goals and interventions was seen to be important because of their interdependence.

The committee highlighted the need to involve family, carers and other social networks in the delivery of interventions because, in their experience, it is one of the key factors for success.

Rehabilitation services for emotional health and mental wellbeing are often provided separately to other rehabilitation services. Therefore, the committee agreed that it is important to ensure good communication and coordination between services, and to refer appropriately.

The committee acknowledged that emotional health and wellbeing needs can fluctuate in people with a chronic neurological disorder. Therefore, they recommended an “opt in” and “opt out” approach for emotional health and mental wellbeing services.

Interventions

Evidence showed that cognitive behavioural therapy and mindfulness-based talking therapy were effective in addressing low mood, anxiety, distress and adjustment difficulties. However, the duration, intensity and method of delivery of the therapies varied from 1 study to another, and the committee was concerned about the quality of the evidence. There was little evidence on acceptance-based interventions for people with a chronic neurological disorder. However, it is widely used in practice and so the committee agreed it could be another option for treating these symptoms.

Evidence demonstrated the benefit of motivational interviewing and supported the committee’s experience of this technique. Additionally, motivational interviewing and psychoeducation interventions are widely used in practice to promote motivation.

Evidence on interventions targeting adaptive dysfunction and behaviours, including positive behaviour support, for people with Parkinson’s disease showed that it helps with mood regulation. Positive behaviour support is widely used in practice for people with a profound chronic neurological disorder whose behaviour challenges, including those with acquired needs. The committee agreed neurobehavioural approaches can help people with any type of chronic neurological disorder and challenging behaviour.

Evidence on creative therapies only covered music therapy as a way to improve cognition rather than emotional health and mental wellbeing. Based on their experience, the committee agreed that creative therapies are useful for people who are having problems with their emotional health and mental wellbeing but find talking therapies difficult.

They also recognised that there are meaningful benefits to individual and group therapy, but the choice should be based on the person’s needs and preferences.

The committee discussed the lack of adaptations of talking therapies to address cognitive or communication deficits in people with a chronic neurological disorder.

They recommended use of memory or communication aids, and adaptation to the number, length and frequency of sessions.

The committee recommended referring to NICE guidance for specific conditions, such as post-traumatic stress disorder and depression, in people with a chronic neurological disorder who are diagnosed with the corresponding condition.

There was limited evidence for children and young people and in people with a functional neurological disorder. The committee, therefore, made recommendations for research on interventions and approaches for improving and sustaining emotional health and mental wellbeing in children and young people with a chronic neurological disorders and in adults with a functional neurological disorder to inform future recommendations.

How the recommendations might affect practice

Currently, the emotional health and mental wellbeing of people with a chronic neurological disorder are often overlooked, and services are usually provided separately from other rehabilitation services. Therefore, additional resources may be needed to enable two-way communication between neurorehabilitation and mental health services.

More consistent consideration of emotional health and mental wellbeing may increase demand for support services and put pressure on existing services. However, not everyone with a chronic neurological disorder will require such support.

Staff in general mental health services may need additional training to understand the challenges faced by people with chronic neurological conditions and deliver appropriate interventions. Better communication between services could improve care and health outcomes, potentially saving costs for the NHS.

Return to recommendations

Cognitive function

Recommendations 1.19.1 to 1.19.12

Why the committee made the recommendations

Principles

The committee agreed that people with a chronic neurological disorder often lack insight into their condition, which can reduce engagement in rehabilitation.

They noted that people with cognitive changes may need support to adjust to cognitive changes. This can help the person redefine their sense of self.

Assessment

The committee discussed the evidence and noted that interventions targeting specific cognitive domains were beneficial.

The committee used their knowledge and experience to identify the cognitive domains that should be assessed and recognised that impairment in one domain may mean impairments in other domains. They highlighted that language deficits often impact on other domains as well as engagement with rehabilitation.

The committee agreed, based on their knowledge and experience, that functional assessments can better capture cognitive issues that are impacting on daily life, as standardised tests in controlled environments, while accurate at detecting cognitive impairments, do not reflect the impact of real-world distractions on cognitive function. Therefore, the committee recommended using both standardised and functional assessments to provide a comprehensive cognitive profile, identifying both strengths and weaknesses.

The committee highlighted the importance of considering the person’s cognitive function before neurological injury or development of a neurological disorder and any other health conditions when assessing cognitive function. They noted that cognitive function may appear adequate but still fall below the levels the person previously had. They also recognised that factors like fatigue, mood, or pain can affect results.

Evidence indicated that people with a chronic neurological disorder sometimes found the assessments tools to be patronising. So, the committee recommended that rehabilitation practitioners should explain what the assessments involve and why they are needed to prevent confusion and feelings of humiliation.

Interventions

The committee noted the importance of strategies to maintain cognitive function, as cognitive decline can have a severe impact on daily life, leading to social isolation and deterioration of the person's well-being.

They also highlighted the need to minimise risk factors for cognitive decline. They recommended providing advice and support on this.

Evidence showed compensatory strategies can help people with memory and learning difficulties to be more independent and have a better quality of life. The committee used this, and their knowledge and experience, to recommend specific strategies and compensatory aids.

They noted the importance of integrating internal and external compensatory strategies to address problems with executive function in everyday life. Internal strategies involve the person taking control of organising, planning and monitoring their behaviour, while external strategies involve external cue aids. Additionally, they discussed how, in their knowledge and experience, changes to the person's environment, such as reducing background noise, can improve both executive function and memory and learning.

The committee highlighted that based on their knowledge and experience people with executive function deficits often struggle with self-managing their cognitive functioning and benefit from family or carer support.

The committee noted that transcranial direct current stimulation (tDCS) and transcranial magnetic stimulation (TMS) are emerging non-invasive techniques aimed at enhancing cognitive function in chronic neurological disorders like multiple sclerosis and Parkinson's disease. While current evidence is insufficient to recommend their use, the committee made a recommendation for research on the effectiveness of tDCS and TMS interventions.

How the recommendations might affect practice

Functional assessment is not standard practice and would require additional resources, including staff training. However, any additional costs may be offset by improved cognitive functioning in people with a chronic neurological disorder, leading to cost savings because of, for example, reduced support needs. Better assessment and consideration of cognitive function may lead to an increase in the number of people accessing cognitive rehabilitation, putting pressure on existing services. However, this is justified based on clinical need. Most recommended interventions to improve or maintain cognitive function are current practice.

Return to recommendations

Speech, language and communication

Recommendations 1.20.1 to 1.20.8

Why the committee made the recommendations

The committee recognised the impact of speech, language and communication impairments on the health and wellbeing of people with a chronic neurological disorder. They were also aware that rehabilitation practitioners often overlook these impairments. To avoid this, they agreed that people should be asked about speech, language and communication difficulties as part of holistic rehabilitation needs assessment.

The evidence did not provide information on how to prioritise assessments for speech, language and communication impairments. The committee noted that some people who have speech, language or communication difficulties are not being assessed by a speech and language therapist. For this reason and based on their experience, they recommended initial screening by a speech and language therapist, with further assessment, if needed.

The committee agreed that urgent assessment is only needed for people with severe speech, language and communication impairments and should cover use of alternative and augmentative communication equipment, if there is a clinical need for it.

Overall, the evidence did not show the effectiveness of one speech, language and communication technique over another (for example, exercises targeting respiration compared to exercises targeting phonation). However, the committee agreed that therapy should be offered, if needed, and can be more effective if framed within the context of the person’s rehabilitation goals. They also agreed it may be helpful for the person to learn functional skills by practising in real-life environments.

The committee recognised that offering speech and language therapy to people who need it can have wider social and economic benefits, for example, by enabling the person to get back to work.

Based on their experience, the committee agreed that speech and language therapists are best qualified to deliver education and training programmes in communication skills for family, carers or others close to the person. These programmes are important as they enable meaningful communication between the person and those most important to them. This may include teaching sign language.

Evidence suggested that electronic voices can sound too robotic to convey emotions. Creating a personalised synthetic voice can reduce the robotic effect, but is costly and not always suitable. The committee advised early referrals to voice banking services for those with voice loss, or likely to lose their voice.

How the recommendations might affect practice

Speech, language, and communication impairments are often currently overlooked. Considering these aspects in holistic rehabilitation assessments will identify more people with such problems, leading to more people accessing further assessment and support services, and an increased demand for speech and language therapists. Improved speech, language and communication may reduce anxiety, depression and social isolation. Other potential benefits include better engagement in rehabilitation, fewer hospital admissions and unplanned care visits, fewer GP visits, and less intensive support from carers and other support services. Potential cost savings from these changes may offset the costs associated with providing more assessments and interventions by speech and language therapists. Improved speech, language and communication may also increase participation in education and employment offering broader social and economic benefits.

Referring people with severe speech, language or communication impairments for assessment for alternative and augmentative communication equipment, if clinically indicated, reflects current practice and is not expected to require additional resources.

There may be more referrals to voice banking services. However, these are usually self-funded or covered by personal independence payments.

Return to recommendations

Eating, drinking and swallowing

Recommendations 1.21.1 to 1.21.13

Why the committee made the recommendations

Assessment and interventions

The committee agreed, based on their knowledge and experience, that people with a chronic neurological disorder may need to be assessed for problems with:

- oral hygiene
- saliva management
- eating, drinking, and swallowing.

The committee recognised that people with motor neurone disease and Parkinson’s disease have specific problems with saliva management. As NICE has produced separate guidance on this, they decided it was important to link to it.

The committee, based on their experience, identified some interventions that can help manage or prevent deterioration in eating, drinking and swallowing, and promote independence and safety. They explained that sensory interventions stimulate the swallowing reflex and can help some people who are eating and drinking by enteral tube to return to eating and drinking by mouth.

Enteral nutrition supports safe, adequate nutrition in people with a chronic neurological disorder and dysphagia. However, the committee highlighted that it could reduce a person’s autonomy and that the NHS tends to use enteral feeding before strictly necessary. They agreed enteral feeding should be a last resort.

Principles of care

Decisions around modified diets or supported eating and drinking, if needed, may impact on a person's ability to live independently or participate in social activities. The committee noted that decisions to switch to restrictive diets or nil-by-mouth are often made early in a person's rehabilitation, without considering the wider impact on them. Given that some people with a chronic neurological disorder can experience a rapid decline in their ability to eat and drink independently, it is important to have timely discussions about their preferences and to capture these as part of advance care plans.

The committee highlighted the importance of respecting personal choice, should an individual decide to eat and drink whilst understanding the risks. It is also important to consider future escalation of risks and needs.

How the recommendations might affect practice

These recommendations reflect standard practice, with no resource impact anticipated.

Return to recommendations

Independent living, equipment and environmental adaptations

Recommendations 1.22.1 to 1.22.9

Why the committee made the recommendations

Most studies on interventions for independent living, including provision of equipment and environmental adaptations, either did not show a benefit or did not report a sustained effect. However, the committee noted that many of the interventions included in the evidence were not sufficiently tailored to participants' rehabilitation needs. Therefore, the committee made general recommendations based on their knowledge and experience. They were unable to make recommendations about specific interventions because they vary widely depending on the person's neurological condition and their circumstances. They made a recommendation for research on approaches to improve or maintain independence with activities of daily living.

Supporting independence with activities of daily living

The committee discussed compensatory aids to support activities of daily living. Their views on the effectiveness of these devices varied. Some found them to be effective, and others reported that some people with a chronic neurological disorder found them confusing to use. They agreed that it was important to offer support to the person in how to use any aids.

The committee noted the importance of supporting independence and autonomy in all aspects of the person's life. This can help prevent decline in physical functioning and promote emotional health and wellbeing. They highlighted that fostering independence should include providing equipment for both postural support and participation in activities of daily living.

Occupational therapy and skills-based learning

The committee highlighted that occupational therapy for people with a chronic neurological disorder should begin before symptoms start to affect daily life. This will help prevent deterioration in independent living skills and allow the person to live independently for longer. Early access gives the person time to learn and develop skills and gain confidence in using equipment. The committee agreed that occupational therapy is most effective when it reflects real-life scenarios (for example, shopping in the community) and is aligned with the person's rehabilitation goals.

Both errorless and error-based learning have distinct benefits, in the committee's experience. Errorless learning supports those with memory impairments and boosts confidence, while error-based learning enhances critical thinking and decision-making. The committee agreed the chosen method should be based on the person's strengths and weaknesses as well as the skills or tasks being trained.

Environmental adaptations, assistive technology and equipment

The committee agreed that environmental barriers to activities of daily living and the need for equipment or environmental adaptations should be identified by carrying out assessments in the home or residential setting.

Evidence showed that costly equipment can be inaccessible without adequate funding or healthcare insurance. While acknowledging the high expense of some equipment and environmental adaptations, the committee noted the availability of funding, such as Personal Independence Payments, to support needs across home, education and workplace settings. They recommended assisting people with a chronic neurological disorder to access these funds or to directly access equipment and environmental adaptations, where applicable.

Environmental adaptations, assistive technology and equipment can be supplied from multiple sources. The committee recognised that delays or gaps in provision can cause significant issues, such as preventing the person from returning home from hospital or travelling independently. Therefore, they agreed that services should collaborate and coordinate effectively to ensure timely delivery of equipment or environmental adaptations.

How the recommendations might affect practice

Rehabilitation practitioners delivering interventions to support independence in daily life require specialised training. Availability of specialists may vary, but sharing expertise between specialist and community rehabilitation services should mitigate the lack of expertise and need for additional training.

Early access to occupational therapy may increase pressure on services. Timely provision of equipment and environmental adaptations may require more collaboration and communication between services. Access to equipment and environmental adaptations, and access to funding currently varies, and may require additional resources to implement.

The committee recognised the potential benefits of increased independence, including mental health and wellbeing, and related cost savings from reduced need for paid carers, prolonged inpatient or residential care and crisis care. There are also broader economic and social benefits from increased engagement with work, education and social activities. Therefore, any additional costs for supporting independence are likely to be offset by the value of these benefits.

Return to recommendations

Rehabilitation to support education for children and young people

Recommendations 1.23.1 to 1.23.6

Why the committee made the recommendations

Evidence showed early communication from healthcare practitioners allows education settings to prepare for potential support needs. The committee agreed this should happen even if rehabilitation needs are not yet confirmed.

Evidence showed that healthcare practitioners have an important role in helping education practitioners to understand the rehabilitation needs of children and young people with a chronic neurological disorder and how they can support them. The committee noted that healthcare practitioners should have conversations with the school or college and update them as prognosis is determined and rehabilitation needs are identified. They should also agree the equipment, adaptations and adjustments necessary to meet the child's needs.

Evidence indicated that it is useful to provide education practitioners with a named contact for the child's rehabilitation. It was found to support effective information sharing and collaboration, and led to better support on behalf of the education setting. Further evidence indicated that information on support needs is often lost when changes happened, such as when a child moves to a different school of college or their teacher changes, and noted this issue is common at key stages. The committee agreed that it was important for reciprocal information sharing to be maintained at all times.

Evidence highlighted that regular review of education, health and care plans is needed to address the evolving rehabilitation and support needs that all children and young people with a chronic neurological disorder will face. This should include discussions about the appropriateness of education settings.

How the recommendations might affect practice

The recommendations reinforce current best practice, with potential resource impact where services are sub-optimal. The committee noted that low-cost strategies could be used to support the implementation. For example, designating an existing healthcare practitioner for ongoing communication with education providers. Overall, significant resource impact is not expected. Any additional costs are likely to be offset by the return and retention of children and young people in education, along with improved social participation, health and wellbeing, and broader social and economic benefits.

Return to recommendations

Rehabilitation and the workplace

Recommendations 1.24.1 to 1.24.9

Why the committee made the recommendations

The committee discussed and agreed the key elements to take into account when assessing a person’s ability to remain to work. They also agreed support should be provided if the person cannot remain or return to work.

Evidence showed that discussions around remaining in, or returning to, work should start as early as possible, ideally involving the employer, because this can help to identify support needs and set expectations. It highlighted the importance of identifying and addressing any potential barriers for return to work, as well as collaborating with other employment professionals in order to access support.

The committee discussed recommendation 1.16.4 in NICE's guideline on stroke rehabilitation in adults, which gives detailed guidance on managing return-to-work, and agreed it was applicable to the population of this guideline.

The committee discussed their experiences of employers carrying out workplace assessments. They agreed that these were a good opportunity to focus on the environmental, cultural and procedural barriers that the workplace may now present to the person.

Evidence showed that although there were benefits to educating employers on chronic neurological disorders, people were worried that disclosing too much information could lead to discrimination. The committee was unable to give details about the sort of information that should not be disclosed. However, they noted that employers should discuss and agree what information to disclose.

The committee agreed that the environment in which people are assessed and vocational rehabilitation is delivered is important. For example, a quiet clinical setting may be suitable for people who are learning new skills, while a busy office environment with cognitive and sensory challenges may provide a more realistic setting for practising skills.

The committee agreed that vocational rehabilitation needs can fluctuate greatly for people with a chronic neurological disorder and so it is important to review this whenever aspects of rehabilitation that impact on work are reassessed. They also discussed that there is need for employers to be proactive so that any future rehabilitation needs can be planned for before they are needed.

The committee highlighted the importance of extending employment or volunteering opportunities for people with a chronic neurological disorder. They acknowledged that failure to do so significantly affects quality of life and national productivity. Therefore, the committee agreed a recommendation for research on support to access employment.

How the recommendations might affect practice

There is considerable variation in the delivery of vocational rehabilitation services. Implementing the recommendations may require a slight reconfiguration of existing services, potentially achievable within current funding, with no significant resource impact anticipated. Interactions between health practitioners and education services are often via email, and fewer face-to-face meetings could be more efficient. Free e-learning modules on partnership working and resources for general practitioners and employers are available to support collaborative working.

Return to recommendations

Participating in social and leisure activities

Recommendations 1.25.1 to 1.25.7

Why the committee made the recommendations

Evidence showed that access to support for social participation for people with a chronic neurological disorder is impacted by other people’s attitudes as well as the person’s perception of these attitudes. For example, people experienced barriers when they believed that healthcare practitioners were uninterested in discussing this aspect of rehabilitation. The committee noted the importance of discussing potential barriers to social participation with the person, as well as working together to explore strategies to manage these barriers. They also highlighted that healthcare practitioners should recognise that social participation goals can often align with simple, everyday activities aimed at fostering relationships.

Evidence showed that people were often unaware of local social clubs and activities. The committee recognised improved mental wellbeing, cognition and physical health as important rehabilitation goals. These are supported by social participation in activities offered by local social clubs and activities.

Evidence showed that people with a chronic neurological disorder may struggle to complete forms to access social participation and that this is made worse if they have cognitive difficulties. They agreed that general practitioners often provide this support, but noted that any healthcare or social care practitioners could do this.

The committee highlighted 2 barriers to social participation that are often overlooked: requirements for adjustments or adaptations and concerns over toileting needs.

People with a chronic neurological disorder can find it challenging and emotional to discuss their condition and what adjustments and adaptations they need. They are often unsure of what to share. The committee recognised that healthcare practitioner support in these conversations is needed.

The committee recognised that people with bladder or bowel incontinence are often deterred from exploring activities outside familiar settings, and this should be taken into account.

Evidence showed that access to community activities may be limited because of poor service availability or travel challenges. The committee agreed that online options should be considered.

How the recommendations might affect practice

Practices to support social participation for people with a chronic neurological disorder vary. Services may need to train staff to ensure they are well-informed and can provide appropriate signposting.

Community services and activities supporting social participation vary across the country. Additional resources may be needed to establish services or address travel challenges. Online options could help to mitigate potential resource impact.

Social participation can reduce isolation and improve wellbeing, which in turn may prevent mental health problems. Thus, interventions to promote social participation are likely to represent value for money.

Return to recommendations

Family life and friendships

Recommendations 1.26.1 to 1.26.3

Why the committee made the recommendations

The committee recognised that people with a chronic neurological disorder often face added challenges with family life and friendships, including parenting and caring relationships. For example, mobility issues can impact on socialising and fatigue can affect caregiving. The committee noted clear benefits to overall wellbeing, mental health and quality of life of maintaining family life and friendships.

The committee agreed that rehabilitation needs and goals around family life and friendships should be treated like any other rehabilitation needs and goals.

The committee agreed that barriers to family life and friendships should be discussed as part of rehabilitation assessment, goal setting and planning.

The committee noted that people with parenting or caring roles face specific physical and emotional demands that need to be considered. They may need support accessing parental support services and targeted rehabilitation to strengthen their parental and caring skills.

How the recommendations might affect practice

The recommendations reflect current best practice and are not expected to have significant resource impact. Services may need to train staff to offer rehabilitation connected with family life and friendships, including parenting and caring relationships. More staff time may be needed to explore these issues. Overall, any additional costs are expected to be offset by the potential benefits of maintaining relationships and their positive impact on overall wellbeing, mental health and quality of life.

Return to recommendations

Intimate and sexual relationships, and sex

Recommendations 1.27.1 to 1.27.11

Why the committee made the recommendations

Evidence showed that there is a lack of information about intimate and sexual relationships, and sex, for people with a chronic neurological disorder and that this adversely impacts intimacy and sexual rehabilitation. The committee noted that even where information is available, it is poorly promoted.

Evidence highlighted that sexual needs were often missed in rehabilitation plans as people were not asked about intimacy and sexual wellbeing. The committee added that people with a chronic neurological disorder were often open to discussions about sexual rehabilitation but felt uncomfortable raising the subject themselves.

Evidence showed that rehabilitation practitioners were not comfortable starting conversations about sexual rehabilitation and intimacy as they did not have the necessary knowledge or skills. The committee agreed that health practitioners needed to improve their skills and confidence by seeking advice and support.

Evidence highlighted a lack of knowledge regarding sexual rehabilitation for health practitioners, including who to refer to. The committee agreed that there is a limit to the level of knowledge and training that non-specialists can expect to obtain, but should know when and how to signpost to appropriate services.

The committee agreed that the topic of intimacy and sexual relationship could raise safeguarding concerns especially for children and young people and people who lack capacity.

The committee agreed that discussions around intimacy and sexual relationships are sensitive and personal, and therefore a person's gender identity, sexual orientation, religion and cultural beliefs should be taken into account to encourage open conversations.

The committee agreed that to set and achieve realistic rehabilitation goals, barriers to intimate and sexual relationships need to be identified and addressed.

They also agreed that methods for gathering initial information should reflect people’s preference as some will prefer in-depth discussions while others will prefer self-reported questionnaires.

The committee agreed that people with a chronic neurological disorder may need support with discussing their disorder and its impact on intimacy with partners.

The committee discussed and agreed a range of measures for addressing rehabilitation needs connected with intimate or sexual relationships and sex. These may relate to healthcare settings, for example, there may be a lack of privacy in residential settings if bedroom doors cannot be closed.

How the recommendations might affect practice

Including intimate and sexual relationship discussions in rehabilitation may require more staff time, leading to more people being identified and accessing treatment services. Some resource implications are likely, but these are unlikely to be significant.

Return to recommendations

Context

A significant number of people live with the long-term consequences of neurological disease and disorders. These include multiple sclerosis (1 in 520 people), Parkinson’s disease (1 in 37 people), neuromuscular disorders and motor neurone disease (1 in 1,000 people), traumatic brain injury (1 in 350 people), spinal cord injury and brain tumours.

Chronic (or long-term) neurological disorders covered in this guideline refer to a large group of conditions that affect the brain, spine or peripheral nerves.

Acquired brain injury: Injuries to the spine from whatever cause that result in neurological impairment. Causes include trauma, tumours, infections, metabolic insults and disorders of the blood supply. The resulting impairments may improve, progress or remain relatively stable over time.

Acquired spinal cord injury: Acute-onset disorders of the peripheral nervous system that cause neurological impairment. These may include inflammatory, autoimmune or paraneoplastic causes. The resulting impairments may improve, progress or remain relatively stable over time.

Acquired peripheral nerve disorders: Acute-onset disorders of the peripheral nervous system that cause neurological impairment. These may include inflammatory, autoimmune or paraneoplastic causes. The resulting impairments may improve, progress or remain relatively stable over time.

Progressive neurological diseases: Disorders that involve a gradual progression of neurological difficulties over time. Examples include Parkinson’s disease, multiple sclerosis, motor neurone disease and Duchenne’s muscular dystrophy. This includes congenital disorders, but this guideline only covers those that result in long term chronic neurological disorders, impairment and symptoms. And, where there is a progressive need for neurorehabilitation. Some of these conditions may not be progressive in their own right but rehabilitation needs change over time, especially in children.

Functional neurological disorders: Disorders that cause a range of disabling neurological symptoms, which include altered awareness, motor and sensory changes; however, symptoms are not explained by a physical or neurological disease.

Rehabilitation is defined by the World Health Organisation as ‘a set of interventions designed to optimise functioning and reduce disability in individuals with health conditions in interaction with their environment’. Functioning and disability are broad terms which are further conceptualised in the International Classification of Functioning, Disability and Health. This framework highlights the relationships and interplay between the following domains:

- health condition
- body structure and function
- activity
- participation
- environmental factors
- personal factors.

Rehabilitation is an overall process composed of individual interventions. These interventions range from the relatively simple, acting at one or a few domains, to complex interventions that may act across several domains. Rehabilitation is not a ‘one size fits all’ process and aims and goals should be identified and agreed with each person to fully inform personalised treatment and therapy programmes.

Rehabilitation can reduce demand on the most costly and intensive parts of the health and social care system. It also supports people and their families and carers to participate economically in society.

Given the large number of diagnostic categories, age groups and healthcare settings, there is wide variation in the delivery of rehabilitation interventions to people with these long-term conditions.

Inpatient rehabilitation for chronic neurological conditions is delivered through a range of services based within the NHS, the private sector and the voluntary sector. Referral criteria for these services are often specific for disease or condition, symptoms, locality or age group.

In the longer term, rehabilitation may be delivered through hospital or community services, including education-based services. It may also be provided by the private or voluntary sectors. Rehabilitation can involve impairment-focused approaches, for example to improve mobility, or a less impairment-specific focus towards functional goals (such as managing personal care or preparing a meal). Referral criteria may include diagnosis, age, or time since injury, or may depend on the purpose or setting of the intervention (for example, vocational rehabilitation). Referral criteria often inform decisions about people's access to specialist rehabilitation services. There are significant variations in service provision and care pathways depending on the condition or injury.

The guideline covers the following activities, services and aspects of care:

- delivery of rehabilitation for people with a chronic neurological disorder
- identification and referral including re-referral
- assessment, rehabilitation planning and review
- effectiveness of rehabilitation interventions aimed at improving activity and maximising independence and wellbeing
- supporting access to education, employment and social participation.

The guideline does not cover

- diagnosis of neurological disorders
- end of life care (where goals are primarily focused on symptom control and comfort)
- management of medical or psychiatric comorbidities
- transitioning of rehabilitation from children's to adults' services.

Finding more information and committee details

To find NICE guidance on related topics, including guidance in development, see the NICE topic page on neurological conditions.

For details of the guideline committee see the committee member list.

ISBN: TBC