NICE National Institute for Health and Care Excellence

NICE guideline

Rehabilitation for chronic neurological disorders including acquired brain injury

NICE guideline

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Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

All problems (adverse events) related to a medicine or medical device used for treatment or in a procedure should be reported to the Medicines and Healthcare products Regulatory Agency using the Yellow Card Scheme.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Contents

This guideline is the basis of QS74.

Overview

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

This guideline does not cover rehabilitation for people with cerebral palsy, dementia, epilepsy, or stroke rehabilitation in adults. For a detailed list of the diseases, disorders and injuries that are included and excluded, see the section on included and excluded chronic neurological disorders.

This guideline should be read in conjunction with recommendations on rehabilitation in the following NICE guidelines, as appropriate:

- brain tumours (primary) and brain metastases in over 16s
- motor neurone disease: assessment and management
- multiple sclerosis in adults: management
- Parkinson's disease in adults

This guideline should also be read in conjunction with the following, as appropriate:

- assessment and early management of head injury, see NICE's guideline on head injury
- hospital and early community-based coordination of rehabilitation for people with traumatic brain injury (as part of multiple injuries), see NICE's guideline on rehabilitation after traumatic injury
- hospital and early community-based coordination of rehabilitation for people with traumatic injury to the spinal cord, see NICE's guidelines on spinal injury: assessment and initial management and rehabilitation after traumatic injury
- 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

- bed-based and home-based intermediate care, see NICE's guideline on intermediate care including reablement.

Who is it for?

- Health, mental health and social care practitioners
- Commissioning groups that design and commission rehabilitation services and care pathways (including local authorities)
- Health, mental health and social care providers and other providers of rehabilitation services in the voluntary, community and social enterprise (VCSE) and private sectors
- People with a chronic neurological disorder, their families and carers, and the public
- People working in related services, including employers, education, housing, leisure, job centres, welfare advice and legal
- Advocates for people with a chronic neurological disorder.

Designing and commissioning rehabilitation services

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.

Health, mental health 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

- integrated health and social care for people experiencing homelessness.

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
- families and carers of people who use them
- voluntary, community and social enterprise (VCSE) organisations that work with people with a chronic neurological disorder
- health, mental health and social care practitioners who deliver these services.

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 are diagnosed
- include potential for lifelong support and monitoring
- operate across hospital and community settings, including people's homes, and where they work, learn and undertake day-to-day activities
- make use of VCSE and private sector providers, including sport and leisure providers
- include 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 young people, 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 that ensure 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 that 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 interventions that facilitate the delivery of rehabilitation for children

- environmental adaptations
- equipment, assistive devices and compensatory aids
- pain and fatigue management interventions
- exercise and physical activity programmes for muscle strength, exercise capacity and physical functioning, and other interventions for 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
- interventions to enable supported self-management
- interventions to support engagement in education, employment, social and leisure activities, parenting, family life, friendships, intimate and sexual relationships, and sex.

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, including education services for children and local voluntary, community and social enterprise (VCSE) organisations.

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

1.3.3 Develop local workforce skills to help build capacity for neurorehabilitation and mental health services for people with a chronic neurological disorder.

1.3.4 Develop protocols to improve communication between neurorehabilitation, mental health and other services involved in delivering and supporting rehabilitation.

1.3.5 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, by using expertise from specialist neurorehabilitation services and maintaining up-to-date information on options for local rehabilitation services.

1.3.6 Ensure that health, mental health and social care practitioners know how to commission high-cost specialist equipment and services.

1.3.7 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, including via telehealth
- share specialist advice and expertise with non-specialist services
- explore provision of general community rehabilitation services supported by specialist neurorehabilitation services.

1.3.8 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
- cultural factors
- 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 from all specialties and sectors, including the voluntary, community and social enterprise (VCSE) and private sector, should communicate and collaborate, 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 who have:

- changing needs outside of planned interventions
- rapidly emerging 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 in community or hospital settings 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 want to discuss their prognosis or rehabilitation needs, or wants to discuss either or both at a later date, offer and initiate further opportunities for discussions.

1.5.4 Following diagnosis or initial treatment for a chronic neurological disorder, the responsible clinician should give the person an initial 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 in community or hospital settings 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 Discharge for people admitted to hospital

Follow NICE's guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs, as appropriate.

1.6.1 At hospital discharge, the responsible clinician should ensure there is both a key clinical contact for medical advice and an initial contact for rehabilitation (unless the key clinical contact will fulfil this role) and inform their GP of these contacts.

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 initial contact for rehabilitation after discharge.

1.6.3 At the earliest opportunity, arrange for the provision of any urgent equipment, assistive technology or 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 discharge for people admitted to hospital.

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 To decide whether holistic assessment is needed, briefly assess all of the following:

- the person's social, psychological, emotional, cognitive and communication needs
- their physical health
- level of impairment
- the impact of their condition on their ability to participate in day-to-day activities.

1.7.3 If holistic rehabilitation needs assessment is not needed, 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).

1.7.4 Put in place processes for timely follow up with the person to check for changes to their symptoms or level of functioning and to decide whether they need holistic needs assessment.

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

Follow NICE's guidelines about supporting people to make decisions about their health, mental health and social care, as appropriate:

- 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 important 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 it is clear that any new rehabilitation needs can be identified through a specific functional needs assessment.

1.8.3 Be aware that a person may have multiple chronic neurological disorders, including a functional neurological disorder alongside another neurological disorder. If this is the case, undertake holistic rehabilitation needs assessment based on the impact of all disorders and agree a single rehabilitation plan.

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

- identify and contact the health, mental health 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 for holistic needs assessment and rehabilitation planning) **and**
- make onward referrals to other health, mental health and social care practitioners if other needs that are not linked to rehabilitation are identified.

1.8.5 The lead practitioner for holistic needs assessment and rehabilitation planning should seek input from health, mental health and social care practitioners and other practitioners (including teachers, social prescribers and equipment providers) to inform the assessment.

1.8.6 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.

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

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

What to cover

1.8.9 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 these have changed or are 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).

1.8.10 In addition to their neurological condition or injury, think about how other health conditions, including mental health conditions, may affect the person's rehabilitation.

1.8.11 Think about the possible impact of any existing medication on impairment (for example, cognitive function) and review medication as part of rehabilitation planning.

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

1.8.13 If the person has 'invisible' or less easily recognisable symptoms or impairments or lacks awareness and insight into the effects of their injury or condition, and therefore struggles to articulate their rehabilitation needs, assess using multiple methods, including observation.

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

1.8.15 Identify rehabilitation interventions that will 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.

1.8.16 Assess the person's functioning, symptoms and impairment in the following areas:

- 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)
- bladder and bowel function (see NICE's guidelines on urinary incontinence in neurological disease: assessment and management and faecal incontinence in adults: management).

1.8.17 Assess for vision and hearing problems and take into account how these might impact the person's rehabilitation.

1.8.18 As part of holistic needs assessment, find out 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.

1.8.19 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, relationships and sex.

1.8.20 Do not exclude someone from any aspect of holistic needs assessment based on their communication, memory, learning or other cognitive difficulties.

1.8.21 Make reasonable adjustments and adaptations to enable a person with communication, memory, learning or other cognitive difficulties to engage in rehabilitation.

Related assessments

1.8.22 Use the NHS continuing healthcare guidance to determine if someone is eligible for continuing NHS healthcare at home.

1.8.23 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.

1.8.24 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.

1.8.25 Be aware that people who have experienced trauma as a direct result of their injury or condition, or prior life experiences, or both, may need adaptations to assessment, rehabilitation and support plans.

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: rehabilitation for 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, including 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 information from discussions with the person (see recommendation 1.9.9), 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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their own homes

- integrated health and social care for people experiencing homelessness.

1.10 Agreeing, delivering and reviewing a coordinated rehabilitation plan

1.10.1 Based on the person's holistic rehabilitation needs assessment and their goals, agree a personalised rehabilitation plan (to include interventions covered by the sections on rehabilitation to maintain, improve or support function and to support education, work, social and leisure activities, relationships and sex, as appropriate) with:

- the person **and**
- those people important to the person's rehabilitation (see recommendation 1.8.5 in the section on initiating holistic rehabilitation needs assessment and who to involve) **and**
- the health, mental health and social care practitioners involved in the person's 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
- how interventions relate to, and interact with, each other
- intervention modifications in line with factors such as developmental age and cognitive abilities
- the role of family, carers or others important to the person in delivering their rehabilitation
- the person's rehabilitation goals and how interventions will deliver these

goals

- who will deliver the interventions
- how practitioners will liaise with one another and work together to enable interdisciplinary working
- the timing of review appointments for reassessing interventions, approaches, rehabilitation needs and 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 in other community settings, and may include telehealth, where appropriate.

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

1.10.6 If the person is in work, education or training, collaborate with their employer or education provider (with the person's consent) to agree and deliver rehabilitation interventions that are relevant to the tasks and activities the person will be undertaking.

1.10.7 Review rehabilitation needs, goals and interventions when people are moving from acute to longer-term rehabilitation and update the plan accordingly.

1.10.8 Regularly review education support plans for adults if these cover rehabilitation provision, especially if 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.

1.10.9 Discuss and agree aspects of rehabilitation that may be delivered at a later date

as well as what might inform decisions about stopping interventions.

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

1.10.11 When rehabilitation ends or aspects of rehabilitation end, agree if follow-up appointments are needed, and whether they will be initiated by the practitioner or the person with the chronic neurological disorder, 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 for the person, including from their family, carers or social network
- ongoing support and care from healthcare and social care services including from voluntary, community and social enterprise (VCSE) organisations.

1.10.12 Decide which practitioners will be involved in follow-up, for example, care coordinator, nurse specialist, key therapist, healthcare assistant or support worker.

1.10.13 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.

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, delivering and reviewing 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

Follow NICE's recommendations about single points of contact for specific chronic neurological disorders, as appropriate, in the sections on:

- information and support at diagnosis in NICE's guideline on motor neurone disease: assessment and management (recommendation 1.2.4)
- communication in NICE's guideline on Parkinson's disease in adults (recommendation 1.1.6)
- coordination of care in NICE's guideline on multiple sclerosis in adults: management (recommendation 1.3.1)
- care needs in NICE's guideline on brain tumours (primary) and brain metastases in over 16s (recommendation 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 function (including executive function) or communication difficulties that impacts their ability to self-manage their condition or navigate rehabilitation services **or**
- an unpredictable or rapidly changing neurological condition **or**
- multiple rehabilitation needs that require rehabilitation across multiple services and areas of care **or**
- the potential to develop new needs around accessing care and there are associated family support needs, such as when a child or young person moves 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 function (including executive function) or communication difficulties that severely impact their ability to self-manage their condition or navigate rehabilitation services **or**
- is unable to advocate for themselves 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, complex mental health needs, misuses drugs or alcohol or has neurobehavioural symptoms that place them at risk of harm to themself or others.

1.11.7 When rehabilitation significantly changes (for example, following a hospital admission) or ends, update the person about their single point of contact (if this is going to change) and make sure they know how to get in touch if and when

new symptoms or impairment require assessment and rehabilitation.

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.

Information, advice and learning as part of rehabilitation

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- multimorbidity
- transition from children 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

- integrated health and social care for people experiencing homelessness.

1.12 Information, advice and learning as part of rehabilitation

1.12.1 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, community and social enterprise (VCSE) organisations that can provide further information and support.

1.12.2 For people with a functional neurological disorder offer information and psychoeducation that:

- reinforce a biopsychosocial approach to managing their disorder
- support an acceptance of the diagnosis
- validate the presence and impact of symptoms while using language and approaches that redirect attention away from them
- avoid reinforcing beliefs that there is structural damage or disease to the nervous system
- focus on the potential for recovery.

1.12.3 Explain what financial support is available to assist with rehabilitation related 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.

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

1.12.5 Continue to offer personalised information and advice 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.

1.12.6 Consider combining and coordinating delivery of different education and training interventions led by different rehabilitation practitioners to help the person, their family and carers, as appropriate, embed learning. For example, teaching cognitive memory strategies alongside use of aids for independent living.

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

- the use of a health or disability passport
- information to share with people working in services the person needs to access (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

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.

Health, mental health 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

- integrated health and social care for people experiencing homelessness

1.13 Pain management

Follow NICE's guidelines on pain, as appropriate:

- chronic pain (primary and secondary) in over 16s: assessment of all chronic pain and management of chronic primary pain.
- neuropathic pain in adults: pharmacological management in non-specialist settings.

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

1.13.2 Proactively support people in managing their pain and ensure that they have adequate analgesia (if appropriate), to facilitate rehabilitation.

1.13.3 Think about the causes of pain and how pain might be managed when discussing and agreeing rehabilitation goals and plans. Take 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 muscle tone and postural management strategies)
- psychological interventions for low mood, anxiety or support with acceptance and adjustment
- interventions to support independent living, including provision of equipment

and environmental adaptations.

1.13.4 Seek specialist advice on pain management for children and young people with chronic or neuropathic pain.

1.13.5 Consider referral to a pain specialist if there is difficulty in identifying the causes of pain or for advice on a biopsychosocial approach to pain management.

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.

1.14 Fatigue

Follow the recommendations on fatigue in the section on symptom management and rehabilitation in NICE's guideline on multiple sclerosis in adults (recommendations 1.5.3 to 1.5.16 and 1.5.19 to 1.5.23), as appropriate.

Assessment

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

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

1.14.3 Take into account the person's awareness and understanding of their fatigue and

its impact when assessing and managing fatigue.

1.14.4 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 problems and sensory symptoms. Seek specialist advice, if needed.

Interventions

1.14.5 Explain to the person how and why their condition or injury may cause fatigue, the factors that can influence fatigue and how fatigue can fluctuate and impact their daily life, including their mood.

1.14.6 Help the person's family, carers and other people important to them to recognise and understand how fatigue affects the person and how to respond to this appropriately.

1.14.7 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.

1.14.8 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.

1.15 Physical activity and exercise

Follow the recommendations about physical activity and exercise for specific chronic neurological disorders or traumatic injury, as appropriate, in the sections on:

- exercise programmes in NICE's guideline on motor neurone disease: assessment and management (recommendations 1.8.5 to 1.8.9)
- physiotherapy and physical activity in NICE's guideline on Parkinson's disease in adults (recommendations 1.7.2 to 1.7.4)
- exercise in NICE's guideline on multiple sclerosis in adults: management (recommendation 1.4.1)
- physical rehabilitation in NICE's guideline on rehabilitation after traumatic injury.

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

- take into account their executive function and levels of fatigue and pain
- think about risks and potential harmful consequences of exercise and physical activity
- think about what level of support and supervision will best meet their needs
- consider supervised and unsupervised exercises (for example, online resources or local subsidised programmes)
- agree a clinically relevant exercise dose (frequency, duration and intensity).

1.15.2 For people with a functional neurological disorder offer activities that encourage and enable recovery of movement and function. These should:

- focus on planned and purposeful movement to achieve a specific outcome (goal-oriented movement) **and**
- acknowledge the presence and impact of symptoms while redirecting attention away from them **and**

- focus on the potential for recovery.

1.15.3 A registered practitioner with expertise in exercise programmes and physical health (for example, a physiotherapist or occupational therapist), and an understanding of the person and the effects of their condition or injury, should develop and oversee the exercise and physical activity programme.

1.15.4 Discuss and agree outdoor or indoor activities that the person could do to maintain or improve their general physical health, led by the person's preferences.

1.15.5 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.

1.15.6 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.

1.15.7 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, social 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.

1.16 Stability, mobility and limb function

1.16.1 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 1.21.8 in the section on occupational therapy and skills-based learning)
- 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).

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

1.16.3 Think about using gaming modalities or virtual reality to help the person engage with training and exercises to improve stability, mobility or limb function.

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

1.16.5 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.

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

1.16.7 Take into account the potential harms of inappropriate use of interventions if these might limit the possibility or extent of recovery, (for example, serial or removal casting), particularly for people with a functional neurological disorder.

1.16.8 Consider 24-hour postural management strategies (for example, regular positional changes, bed positioning, wheelchair and seating systems, arm supports and splints) if the person is:

- not able, or is less able, to sit up or stand up unaided or move independently, **and**
- at risk of skin breakdown, pain, sleep disturbance, respiratory dysfunction or muscle or joint contracture.

Treadmill gait training

1.16.9 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.

1.16.10 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.

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

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

Electrical stimulation

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

1.16.14 If the person has muscle weakness of the lower limbs, caused by an upper motor neurone lesion, consider functional electrical stimulation in addition to gait training. See also NICE's interventional procedures guidance on functional electrical stimulation for drop foot of central neurological origin.

Interventions for vestibular problems

1.16.15 If vestibular problems are suspected, provide central and peripheral vestibular assessment, and, if needed, exercises or procedures such as ocular motor exercises for stability or canalith repositioning manoeuvres.

For a short explanation of why the committee made 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.

1.17 Emotional health and mental wellbeing

Follow NICE's guidelines on specific mental health conditions, as appropriate:

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

Principles of assessment, referral and intervention selection

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

1.17.2 A registered mental health practitioner (for example, a psychologist, psychiatrist or mental health nurse) with an understanding of the person and the effects of their condition or injury, should oversee assessment for emotional health and mental wellbeing and develop and oversee the emotional health and mental wellbeing element of the person's rehabilitation plan.

1.17.3 Be aware that neurological injuries and conditions can result in:

- neurobehavioural disturbance
- neurobehavioural changes such as apathy, disinhibition and perseveration
- difficulties with emotion regulation
- abrupt fluctuations in a person's emotional state, known as emotional lability.

1.17.4 Assess emotional health and mental wellbeing, behaviour and cognitive function

together (see the section on cognitive function), if completing a combined neuropsychological assessment.

1.17.5 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.

1.17.6 If an assessment shows that a person's emotional health and mental wellbeing are negatively impacted by unmet needs in other areas of rehabilitation, follow the other recommendations in this guideline to meet those needs.

1.17.7 Work with the person's family, carers, social networks and people important to the person when agreeing the most appropriate interventions to improve or sustain emotional health and mental wellbeing.

1.17.8 Ensure that goals and interventions for emotional health and mental wellbeing are agreed within the context of other rehabilitation goals and interventions and think about the impact of emotional health and wellbeing on the progress of other rehabilitation goals.

1.17.9 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
- voluntary, community and social enterprise (VCSE) sector
- education services (for example, for children and young people, those delivered by a special educational needs coordinator or through an emotional literacy support assistant programme).

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

1.17.11 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

1.17.12 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.

1.17.13 If 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, motivational interviewing and cognitive behavioural approaches.

1.17.14 When delivering talking therapy, 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
- the type of intervention (for example, CBT or mindfulness) and form of delivery (for example, online or face-to-face interventions).

1.17.15 If the person has difficulty engaging in talking therapy because of cognitive or communication problems, or if speaking is not the person's preferred way of communicating, consider creative therapy (for example, music, art or drama therapy).

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

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

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.

1.18 Cognitive function

Principles

1.18.1 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.

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

1.18.3 For a child or young person, repeat cognitive assessments to track cognitive development and to understand how their condition or injury might impact their academic attainment and developmental trajectory.

Assessment

1.18.4 A registered practitioner with expertise in neuropsychology (for example, a clinical psychologist, counselling psychologist or neuropsychologist), and an understanding of the person and the effects of their condition or injury, should oversee and interpret cognitive assessments and oversee the cognitive functioning element of the person's rehabilitation plan.

1.18.5 Assess cognitive function, emotional health and wellbeing and behaviour (see the section on emotional health and mental wellbeing), if completing a combined neuropsychological assessment.

1.18.6 Be aware that emotional disturbance (for example, low mood, anxiety and

psychological trauma) can impact cognitive function.

1.18.7 If cognitive communication disorder is suspected, assess and plan cognitive rehabilitation at the same time as speech and language therapy (see the section on speech, language and communication).

1.18.8 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.

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

1.18.10 For people with a functional neurological disorder consider replacing standard cognitive tests with observation and dynamic testing.

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

- the person's sensory, cognitive, intellectual and communication abilities 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, the effects of physical or psychological trauma or pain may affect testing and assessment

- the person's cultural, linguistic and educational background
- the impact of any other health conditions on testing and assessment.

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

Interventions

1.18.13 Plan cognitive rehabilitation based on the results of the cognitive assessment, taking into account

- everyday problems with cognitive function
- any interaction between the domains listed in recommendation 1.18.9
- the person's preferences
- the suitability of group or individual activities
- the person's retained and emerging cognitive skills
- the input of family, carers and other people important to the person and involved in their rehabilitation.

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

1.18.15 Offer advice and support to help the person 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. Refer people to relevant healthcare practitioners, if needed.

1.18.16 Discuss and agree ways to help the person to manage difficulties with memory and learning in daily life. This may include compensatory aids (for example, paper diaries, electronic calendars or smartphone apps) and activities to restore or maintain memory and learning (for example, virtual reality or computerised

cognitive tasks).

1.18.17 To manage the impact of executive function difficulties, discuss and agree internal and external compensatory strategies and changes to the person's environment.

1.18.18 Explain compensatory strategies to the person's family or carers and other people who are important to them and involved in their rehabilitation 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: rehabilitation for cognitive function.

1.19 Speech, language and communication

Follow the recommendations for specific chronic neurological disorders, as appropriate, in the sections on:

- nutrition and gastrostomy in NICE's guideline on motor neurone disease: assessment and management (recommendations 1.11.1 to 1.11.6)
- speech and language therapy in NICE's guideline on Parkinson's disease in adults (recommendations 1.7.7 to 1.7.9).

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

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

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

1.19.4 Offer therapy that supports functional change for identified speech, language and communication needs, focusing on the person's rehabilitation goals (see the section on goal setting).

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

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

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

1.19.8 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.

1.20 Eating, drinking and swallowing

Follow the recommendations for specific chronic neurological disorders, as appropriate, in the sections on:

- equipment and adaptations to aid activities of daily living and mobility in NICE's guideline on motor neurone disease: assessment and management (recommendations 1.10.1 to 1.10.10)
- nutrition in NICE's guideline on Parkinson's disease in adults (recommendations 1.7.10 to 1.7.15).

Assessment and management

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

1.20.2 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).

1.20.3 A registered practitioner trained in dysphagia (for example, a speech and language therapist) 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.

1.20.4 To prevent deterioration in, or sustain or improve, the person's ability to eat, drink and swallow, provide 1 or more of the following:

- advice on the best position and posture for eating and drinking
- speech and language therapist-led interventions to improve swallowing safety, including swallowing manoeuvres (for example, the supraglottic swallow and effortful swallow)

- rehabilitation techniques to regain the ability to swallow (for example, the Shaker exercise, the Masako manoeuvre, expiratory muscle strength training and neuromuscular retraining)
- 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 nil by mouth.

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

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

1.20.7 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 best interests or advance directives if they lack capacity. For recommendations on screening, indications and interventions for nutrition support, see NICE's guideline on nutrition support for adults.

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

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

Principles of care

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

1.20.10 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.

1.20.11 When assessing the risks of eating and drinking by mouth:

- take account of the person's wishes about what, and how, they eat and drink, and respect these wishes wherever possible
- ensure the person and their family and carers understand any risks involved and provide information to inform decision making (for example, if there are indicators of dysphagia or risks of aspiration or choking)
- explain that decision making must be based on the provision of safe care
- provide appropriate safety guidance and advice about eating and drinking by mouth.

1.20.12 Anticipate and address future escalation of risks and needs around eating and drinking.

1.20.13 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.

1.21 Independent living, equipment and environmental adaptations

Follow NICE's guidelines about home care and preventing falls for older people who also have a chronic neurological disorder, as appropriate:

- home care: delivering personal care and practical support to older people living in their own homes
- falls: assessment and prevention in older people and in people 50 and over at higher risk.

Follow the recommendations about equipment and adaptations to aid independence in activities of daily living for specific chronic neurological disorders, as appropriate, in the sections on:

- equipment and adaptations to aid activities of daily living and mobility in NICE's guideline on motor neurone disease: assessment and management (recommendations 1.10.1 to 1.10.8)
- information and support as multiple sclerosis becomes more advanced in NICE's guideline on multiple sclerosis in adults: management (recommendation 1.2.15).

Follow the recommendations about occupational therapy for specific chronic neurological disorders, as appropriate, in the sections on:

- occupation therapy in NICE's guideline on Parkinson's disease in adults (recommendations 1.7.5 to 1.7.6)
- information and support as multiple sclerosis becomes more advanced in NICE's guideline on multiple sclerosis in adults: management (recommendation 1.2.16).

Follow NICE's guidelines on bladder and bowel management, as appropriate:

- urinary incontinence in neurological disease: assessment and management
- faecal incontinence in adults: management.

Supporting independence with activities of daily living

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

1.21.2 A registered practitioner (for example, an occupational therapist), with an understanding of the person and the effects of their condition or injury, should develop and oversee the element of the person's rehabilitation plan concerned with improving or maintaining independence with activities of daily living.

1.21.3 Teach and support the person to use compensatory aids to improve or maintain independence with activities of daily living (see also recommendation 1.18.16 in the section on cognitive function).

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

1.21.5 Take into account the potential harms of inappropriate use of equipment, compensatory aids, assistive devices and adaptive approaches if these might limit the possibility or extent of recovery, particularly for people with a functional neurological disorder.

Occupational therapy and skills-based learning

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

1.21.7 When providing occupational therapy, use settings and scenarios that are appropriate for the person's rehabilitation goals.

1.21.8 When delivering skills-based learning or task-based training, use error-based or errorless techniques depending on the person's sensory, perceptual, motor planning and cognitive strengths and weaknesses and the skill or task the training is focusing on.

Environmental adaptations, assistive technology and equipment

1.21.9 Identify and address any environmental barriers to activities of daily living in the home or residential setting. This could involve moving furniture or commonly used cooking or bathing items to a more accessible place, providing moving and handling equipment (for example, a hoist) and environmental adaptations (for example, using ramps where steps exist).

1.21.10 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 from voluntary, community and social enterprise (VCSE) organisations.

1.21.11 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, relationships and sex

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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.

Health, mental health 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

- integrated health and social care for people experiencing homelessness.

1.22 Rehabilitation to support education for children and young people

Follow NICE's guideline on disabled children and young people up to 25 with severe complex needs, as appropriate.

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

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

1.22.3 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.

1.22.4 Ensure there is:

- a named rehabilitation 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 nursey, school or college, or their teachers change.

1.22.5 Discuss at regular intervals whether the nursery, school or college is still suitable for the child or young person or whether a different education setting is needed.

1.22.6 Regularly review education, health and care plans if they include rehabilitation provision, especially if the child or young 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 and evidence review L: support to access education.

1.23 Rehabilitation and the workplace

Follow NICE's guideline on workplace health: long-term sickness absence and capability to work, as appropriate.

See also the section on 'what access to work is' in GOV.UK's Access to Work: get support if you have a disability or health condition.

These recommendations apply to paid, including self-employment, and voluntary work.

1.23.1 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.

1.23.2 If the person is unable to remain in, or return to, a specific work role, provide support to enable them to leave work or change their role.

1.23.3 Discuss remaining in, or returning to, work with the person and their employer as

early as possible and:

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

1.23.4 When planning return to work follow 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.

1.23.5 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.

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

1.23.7 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.

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

1.23.9 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.

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 and evidence review M: support to access employment.

1.24 Participating in social and leisure activities

1.24.1 Talk to the person about any barriers preventing them from achieving their social participation goals and work together to overcome these barriers. Barriers could relate to:

- the need for support, which may be practical, physical, emotional or cognitive
- the impact of other people's attitudes and behaviours
- cultural, social or socioeconomic factors
- availability of suitable facilities.

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

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

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

1.24.5 Support the person to explain to organisers of social or leisure clubs or activities, including faith-based activities, any adjustments and adaptations needed to enable them to access the venue or activity.

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

1.24.7 Consider online options for social activities if in-person activities are scarce, for example, in rural areas, or if 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 and evidence review N: support for social participation.

1.25 Family life and friendships

1.25.1 Offer the person the opportunity to discuss rehabilitation needs and set rehabilitation goals connected with family life and friendships, including relationships at school and home for children and young people, and parenting and caring relationships.

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

1.25.3 If the person needs support to maintain and develop parenting and caring relationships:

- discuss how they feel about these relationships in the context of their rehabilitation needs
- address any physical, cognitive, communication, emotional or social barriers to parenting and caring responsibilities
- help them to access parental support services, if needed
- provide 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 and evidence review N: support for social participation.

1.26 Intimate and sexual relationships, and sex

1.26.1 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.

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

1.26.3 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.

1.26.4 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 or couples counselling, or continence management. See also the section on interventions for emotional health and wellbeing.

1.26.5 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.

1.26.6 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.

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

1.26.8 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.

1.26.9 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.

1.26.10 Address rehabilitation needs connected with intimate or sexual relationships and sex through:

- 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.

1.26.11 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 and evidence review N: support for 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.

Acquired brain injury

Injury to the brain that results in neurological impairment. Causes include trauma, tumours, infections, metabolic insults and disorders of the blood supply.

Acquired peripheral nerve disorders

This includes acute-onset disorders of the peripheral nervous system that result in neurological impairment. Causes may be inflammatory, autoimmune or paraneoplastic causes.

Acquired spinal cord injury

Injury to the spine that results in neurological impairment. Causes include trauma, tumours, infections, metabolic insults and disorders of the blood supply.

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

All rehabilitation interventions and services delivered by rehabilitation practitioners in settings outside of hospital, including the person's home. These are often non-specialist

services and may not have expertise in working with people with chronic neurological disorders.

Compensatory aids

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

Complex case manager

A named health, mental health or social care practitioner (for example, a social worker) with specialist knowledge in inpatient and community-based rehabilitation and support, including education or training support for children and young people, if needed. They must be able to engage and commission services, monitor them, and integrate input from various different services and professions.

A complex case manager works with people who have severe, complex and long-term rehabilitation needs and impaired cognitive or executive function, are unable to advocate for themselves, have serious comorbidities, learning disability, complex mental health needs, misuse drugs or alcohol or neurobehavioural symptoms that place them at risk of harm to themselves or others.

They provide advice, proactive support and signposting, coordinating rehabilitation across multiple services provided by therapists, support workers and other health, mental health and social care practitioners, as well as liaising with community services such as transport and housing services. They assess rehabilitation needs, consider multiple clinical assessments, identify priorities, and create tailored rehabilitation plans, acting as advocates and promoting inclusion. Complex case managers review rehabilitation plans as needed and offer ongoing support as circumstances change.

Where assigned, a complex case manager would also cover any responsibilities of a key contact or key worker that are not covered here.

Errorless and error-based learning

Errorless learning is an instructional method aimed at preventing mistakes during the learning process. It involves giving clear, step-by-step guidance and prompts to ensure successful completion of tasks without errors.

Error-based learning, for example trial and error, allows mistakes to be made as part of the learning process. These errors help people identify and correct misunderstandings, fostering deeper understanding and long-term retention of learning.

Executive function

A set of cognitive processes that help direct and coordinate other cognitive functions. These processes help a person to plan, meet their goals, display self-control, follow multiple-step directions even when interrupted, and stay focused despite distractions. Executive function also includes the ability to draw conclusions from known or assumed facts (reasoning ability), initiate purposeful behaviour, and demonstrate insight into one's own actions and limitations. These abilities are primarily associated with the frontal lobes of the brain and are essential for adaptive, goal-directed behaviour.

Impairments in executive function are common in people with acquired brain injury and may not be immediately apparent, especially in structured or familiar environments. Failure to recognise deficits in initiation and insight can result in unmet needs and increased vulnerability, as these impairments may not be self-reported or observable without specialist assessment.

Functional activity

Tasks performed as part of a person'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 a person's ability to perform a specific activity in their daily life. Functional assessments may cover activities of daily living in the home; activities involving memory or cognition skills; psychosocial and behaviour issues, and communication.

Functional neurological disorders

Functional neurological disorders can cause a range of disabling neurological symptoms, which include altered awareness, and motor and sensory changes. However, symptoms are not explained by a physical or neurological disease.

Health or disability passport

Allows a person with a long-term health condition or disability to record information about themselves and the support they need, so that this can be shared with others. It is carried by the person and can be used in the workplace, in education and when accessing any other service. It helps to explain the necessary adjustments and accommodations required by the person in order to access services or participate.

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.

Initial contact for rehabilitation

The initial contact for rehabilitation is a named practitioner assigned by the responsible clinician following diagnosis or initial treatment for a chronic neurological disorder where potential rehabilitation needs are identified.

They may be temporary and may also be assigned at hospital discharge.

This role is distinct from the lead practitioner for holistic needs assessment and rehabilitation planning. It is also distinct from the single point of contact, who is assigned after holistic needs assessment and on the agreement of a rehabilitation plan.

The role of the initial contact for rehabilitation may be undertaken by a wide range of practitioners, for example:

- nurse

- physiotherapist
- occupational therapist
- clinical psychologist
- neurologist
- GP
- rehabilitation physician
- special educational needs coordinator
- allied health professional
- family support worker
- social worker
- case manager
- disability paediatrician
- speciality-specific coordinator, for example, a neuro navigator.

The role can be hospital- or community-based (for example, in a community neurorehabilitation team) and provides a link to rehabilitation services, early service delivery and early assessment coordination before a lead practitioner for holistic needs assessment and rehabilitation planning is agreed.

Internal and external compensatory strategies

Internal compensatory strategies involve using cognitive techniques or skills to adapt to, or overcome, cognitive 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 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 rehabilitation services as needs emerge. They seek information and input from others if they cannot offer advice directly. This contact should remain in place even when the person is not receiving active rehabilitation.

Key worker

A key worker is a named health, mental health or social care practitioner. This role may change along the rehabilitation care 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 mainly qualified NHS staff currently undertaking this role, but practice varies in whether people are assigned key workers.

Where assigned, a key worker would also cover any responsibilities of a key contact that are not covered here.

Lead practitioner for holistic needs assessment and rehabilitation planning

The lead practitioner is the person who leads on and coordinates the holistic needs assessment, goal setting, the agreement of a personalised rehabilitation plan and the appointment of a key contact, key worker or complex case manager. They may also be the initial contact for rehabilitation or responsible clinician or key clinical contact (as referenced in the recommendations) and they would usually require knowledge or experience of working with people with the same or related disease, disorder or injury.

This role is distinct from the single point of contact, which is assigned after holistic needs assessment and on the agreement of a rehabilitation plan.

The role of the lead practitioner may be undertaken by a wide range of practitioners, for example:

- nurse
- physiotherapist
- occupational therapist
- clinical psychologist
- neurologist
- GP
- rehabilitation physician
- special educational needs coordinator
- allied health professional
- family support worker
- social worker
- case manager
- disability paediatrician
- speciality-specific coordinator, for example, a neuro navigator.

The role can be hospital- or community-based (for example, in a community neurorehabilitation team) and provides a link to services, early service delivery and assessment coordination before a rehabilitation plan is finalised and before the most appropriate single point of contact is agreed.

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.

Progressive neurological disease

Disorders that involve a gradual progression of neurological difficulties over time.

Rehabilitation

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'. Rehabilitation helps a person to be as independent as possible in everyday activities and enables participation in education, work, recreation and meaningful life roles such as taking care of family. It does so by working with the person and their family to address underlying health conditions and their symptoms, modifying their environment to better suit their needs, using assistive products, educating to strengthen self-management, and adapting tasks so that they can be performed more safely and independently. Together, these strategies can help an individual overcome difficulties with thinking, seeing, hearing, communicating, eating or moving around.

Rehabilitation is defined by the British Society of Rehabilitation Medicine as 'a process of assessment, treatment and management with ongoing evaluation by which the individual and their family/carers are supported to achieve their maximum potential for physical, cognitive, social and psychological function, participation in society and quality of living'.

Rehabilitation plan

An agreement about the rehabilitation treatments and approaches that will help the person maintain, improve or support function, live as fully and independently as possible, and to achieve their rehabilitation goals.

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

Rehabilitation practitioners include but are not restricted to:

- occupational therapists
- physiotherapists
- orthotists and prosthetists
- consultant physicians in rehabilitation medicine
- nurses trained in rehabilitation
- disability paediatricians
- technical instructors
- rehabilitation and therapy assistants
- education support staff
- practitioner psychologists (including clinical psychologists, neuropsychologists, education psychologists)
- neuropsychiatrists
- creative arts therapists (for example, music, art and drama)
- mental health nurses
- social workers
- speech and language therapists
- dieticians
- 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 rehabilitation needs assessments and rehabilitation plans.

Responsible clinician

The doctor or healthcare professional responsible for the person's treatment and care in relation to their neurological disease, disorder or injury either in hospital or in the community. For the purposes of this guideline, they are responsible for making sure the person has an initial contact for rehabilitation even if rehabilitation needs have not yet emerged.

Single point of contact

This 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 decision about the most appropriate single point of contact is made following the completion of the holistic rehabilitation needs assessment and incorporated into the rehabilitation plan.

The type of single point of contact needed will vary dependent on the person, their circumstances, whether they are at home, in a residential or inpatient (hospital) setting and the intensity of other medical or social care they may be receiving.

Decisions should be based on the complexity of needs, service organisation and abilities of the person to coordinate their own care as identified at holistic needs assessment (see also the definitions for key contact, key worker and complex case manager and the criteria for decision making in the recommendations in section 1.11).

A single point of contact must remain even when the person is not receiving rehabilitation, to ensure access to services as needs emerge.

Skills-based learning

Emphasises the development of specific skills required to perform certain tasks. This type

of learning is often hands-on and practical and involves directly applying and practising the skills needed for a particular job or activity, such as technical skills, communication, or problem-solving.

Social cognition

Describes a variety of disparate cognitive, affective, and behavioural abilities that interact and contribute to a person's interactions with other people. It includes how people understand and make sense of social interactions, such as the recognition of emotions, intentions, beliefs, and behaviours in themselves and others. Social cognition plays a key role in effective communication, empathy, and social functioning, and is particularly relevant in the assessment and support of people with neurodevelopmental or cognitive conditions.

Specialist neurorehabilitation services

Any rehabilitation service that is tailored to treat and care for people with a chronic neurological disorder, including services for any disease, disorder or injury that can result in neurological impairment or disabling neurological symptoms (for example, any rehabilitation service based within a neuroscience centre). This includes specialised rehabilitation services that support people with a complex disability whose rehabilitation needs cannot be fully met by general community rehabilitation services. It would also cover specialist advice and expertise on care or equipment.

Standard cognitive tests

Standardised assessments that evaluate specific mental functions (also known as cognitive processes), such as memory, attention, language, executive function and problem-solving. These tests aim to measure how well a person's brain processes information, rather than how they perform everyday tasks. Cognitive tests assess internal cognitive processes and are used to evaluate how cognitive abilities translate into real-world activities and daily living skills.

Task-based training

A teaching approach where people engage in activities that replicate real-world tasks that

are part of their daily 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.

Trusted assessment

Where a trusted assessor – someone acting on behalf of, and with the permission of, multiple organisations – carries out an assessment of a person's health, mental health or social care needs, or all of these.

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 or job roles, retraining or providing support in leaving a role and finding alternative occupations.

Working memory

The cognitive system responsible for temporarily storing and manipulating information needed for complex tasks such as reasoning, comprehension, and learning. It helps people 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 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 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 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 a chronic neurological disorder

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 mental 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 for 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 for 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.

9 Complex case management for people with a chronic neurological disorder

What is the effectiveness and cost-effectiveness of complex case management in the delivery of rehabilitation 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 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 I: clinical case management.

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 1.12.7 and 1.22.1 to 1.26.11 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 agreed that services should be wide-ranging and designed with users and health, mental health and social care 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 only provided in the short term for specific symptoms. This is 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 symptom presentation or diagnosis, will enable more timely access to services as future needs will be better anticipated.

Evidence highlighted that a comprehensive model of rehabilitation should encompass health, mental health and social care and the voluntary, community and social enterprise (VCSE) sector. The committee recommended that services operate across all health, mental health and social 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 the community 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 geographical 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, and with lifelong support and care in mind, may require additional resources and put pressure on existing services. However, the need for extra resources may be partially offset by using existing resources more efficiently and effectively. Implementing the recommendations may enable timelier access to assessment and care, which may reduce reliance on expensive crisis care, potentially offsetting some of the additional costs.

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 navigating rehabilitation services can be challenging. 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. This 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 these 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 1.3.8

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 should start 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. Mental health 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.

The committee agreed that is also important for neurorehabilitation and mental health service providers to build expertise and capacity in the workforce to better serve people with a chronic neurological disorder. This should be done by developing workforce skills.

They also flagged the importance of developing protocols to improve communication between services involved in rehabilitation, including mental health services.

Evidence showed that increasing levels of knowledge of chronic neurological disorders within primary care settings can help improve identification of rehabilitation needs and increase necessary referrals. It also showed that healthcare practitioners often focus on physical and visible symptoms, and some have prejudged ideas about how certain disorders and injuries will respond to rehabilitation treatments. This can be a barrier to some people accessing an appropriate rehabilitation service and 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 that often people could not access appropriate rehabilitation services because specialist centres and services were limited. 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 noted the resource impact of increasing the numbers of 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 and, while some people like group settings, others do not. The committee discussed a wide range of factors that should be considered in order to increase engagement with group activities.

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 shortage of appropriately skilled staff within neurorehabilitation services. There is also 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. 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 formal training. This approach is already in place in some areas and is not expected to require significant additional resources.

The NHS already funds high-cost specialist equipment and services. However, provision is limited, with long waiting times. Raising awareness among health and social care practitioners about how to commission such equipment and services could improve access and increase demand. Since funding is already available and not everyone will require high-cost specialist equipment, the additional resources are unlikely to be significant.

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 moving 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 operating 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 the ability to request a review of their needs. The committee agreed that a simple, reliable process should be in place for people to re-access services, aiding timely intervention and reducing the chances of further functional deterioration.

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

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 enable access to rehabilitation services, delays can occur because of capacity issues, time taken to assess needs or lack of awareness of available services among practitioners. 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 in community or hospital settings 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 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 for discussion offered as needed.

Evidence showed the importance of a single contact point for rehabilitation. The committee agreed that the responsible clinician should give the person and their GP a contact for rehabilitation at the earliest opportunity, even before rehabilitation is due to start, 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, an early needs assessment is crucial as some diagnoses can take years to establish.

Some people are given an initial 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

Discharge for people admitted to hospital

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 an initial contact for rehabilitation is needed even before rehabilitation begins because rehabilitation can be anticipated as a requirement for long-term conditions at some point in the future. This should be communicated to the person's GP to ensure continuity of information.

When rehabilitation assessment or treatment has begun prior to discharge, a member of the inpatient multidisciplinary team might be the rehabilitation contact during the hospital stay. However, during the discharge process, it is important to agree who is best placed to take on this role after discharge.

Evidence showed that poor coordination during discharge led to delays and unmet needs at home. The committee agreed that delays in arranging equipment, assistive technology 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 the 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.

The NHS already provides pathways and funding for equipment, assistive technology and environmental adaptations. However, staff shortages often delay assessments and subsequent adaptations. Therefore, more staff may be needed. Since funding is already available for equipment, increasing staff capacity may enable earlier access to essential support and avoid costly discharge delays, potentially offsetting any additional costs.

Return to recommendations

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

Recommendations 1.7.1 to 1.7.4

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.

The committee agreed that a brief, informal assessment should be undertaken to decide if holistic needs assessment is needed.

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

Follow-up appointments should be organised to check symptoms and level of functioning in areas that are less easy for people to notice themselves, or for people who cannot initiate their own review.

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 1.8.25

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 the person 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. They noted that this support needs to be 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. This is often when 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.

The committee noted that people can present with multiple chronic neurological disorders. In these cases, one disorder can impact the assessment and rehabilitation of another. Practitioners should consider all disorders during the assessment, the likely interactions between them, and design a plan that will encompass all disorders.

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, mental health and social care practitioners. This person and the other practitioners involved should then agree the most suitable person to lead the assessment going forward.

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 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 the person is undergoing or waiting for assessments for other potential needs. This is to ensure timely rehabilitation planning and delivery.

What to cover

Evidence highlighted that holistic rehabilitation needs assessment for people with a chronic neurological disorder requires an individualised approach. The committee 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. They also noted that conversations about challenges in the person's life may uncover difficulties and their underlying causes and help identify rehabilitation needs.

People with impairments that are less easy to recognise may need assessments using multiple methods to capture the full extent of their rehabilitation needs.

Medication can have an impact on the person's symptoms or impairments, so the committee agreed medication reviews should form part of rehabilitation planning.

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.

It also showed the importance of having honest conversations about rehabilitation needs that are likely to get worse, and the need to involve family or carers in the planning process, if appropriate. The committee agreed that it was necessary 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.

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 communication, memory, learning or other cognitive 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 need to complete the NHS continuing healthcare tools. For children and young people, rehabilitation support may be provided through an education, health and care plan (EHCP) 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.

They recognised that people who have experienced trauma, either as a consequence of their injury or condition, or life experiences, or both, may not engage in rehabilitation in the same way as someone who has not experienced trauma. They agreed that adaptations to assessment, rehabilitation and support plans may be required for these groups of people.

How the recommendations might affect practice

Capacity may need to increase to meet 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, positively impacting mental health and emotional wellbeing, and reducing related NHS costs.

The NHS already provides pathways and funding for services like NHS continuing healthcare, and education, health, and care plans (EHCPs) 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 people's engagement with goal setting.

People with a chronic neurological disorder were also found to be less motivated 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 management of their condition.

Evidence showed that children with communication difficulties had problems participating in goal setting. 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.

Goal setting was found to be more realistic when there were honest discussions 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.

The need to review goals was found to evolve over time, with frequent reviews and a focus on physical rehabilitation early on, followed by a shift towards 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 and was better when goals were relevant. Regular reviews of goals and plans will keep them in line with the child's or young person's growth and developmental stage. The committee agreed that regular reviews of goals and plans was beneficial to adults too.

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.

Inadequate goal setting may lead to 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, delivering and reviewing a coordinated rehabilitation plan

Recommendations 1.10.1 to 1.10.13

Why the committee made the recommendations

Evidence showed that collaboration between health, mental health and social care practitioners helped to facilitate holistic rehabilitation needs assessments. It also highlighted that rehabilitation planning and delivery should involve family members or other people important to the person to achieve the best possible outcomes.

Evidence showed that rehabilitation planning should be tailored to the person, and that people with a chronic neurological disorder were unhappy with generic rehabilitation packages. The committee agreed that the plan should include any modifications to interventions.

People with a chronic neurological disorder were found to be dissatisfied with the short timeframe of rehabilitation 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 noted that people can feel overwhelmed if a number of different interventions start 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. The committee agreed that rehabilitation practitioners should decide how they will collaborate and when to hold review appointments.

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 and may not benefit from rehabilitation, stemming from the belief that rehabilitation is for managing disability rather than optimising or maintaining functioning.

Some people with a chronic neurological disorder were found to prefer rehabilitation 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 preferences.

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 correct, up-to-date information when treating a person and so providing ineffective or untimely treatments.

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.

Evidence showed that in many cases the need to review goals decreased throughout rehabilitation, as goals became longer-term. Reviews were more frequent at the start of rehabilitation when goals tended to be more short-term and rehabilitation needs were still emerging.

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 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.

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

The committee agreed the factors that should be taken into account when deciding whether a follow-up appointment would be needed, who should initiate it, and who should be involved. Deciding who will be involved will allow for good communication and coordination.

They also noted 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.

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. Earlier and prolonged rehabilitation may also require additional staffing.

However, effective rehabilitation may help maintain people's independence, reduce the need for paid carers, positively impact mental health, and reduce 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, which offers broader social and economic benefits.

Reviewing rehabilitation plans and follow-up 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 review rehabilitation plans, agree and carry out follow-up appointments and ensure access to necessary interventions, equipment, technology and advice.

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 1.11.7

Why the committee made the recommendations

Evidence showed that a single point of contact can help people with a chronic neurological disorder coordinate their rehabilitation and provide information on accessing different services. It also showed that people want assistance with navigating the rehabilitation system and building 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.

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 to review this if their needs change. They agreed that only people unable to coordinate their own rehabilitation should receive more intensive levels of support. They recognised that the level of support needed may change during rehabilitation and extra support may only be needed on a temporary basis.

The committee 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 discussed and agreed the criteria for assigning a key worker and complex case manager. They agreed that the person must have at least one of the severe and complex needs listed for the assignment of a complex care manager to be considered. But they also agreed that the more of these criteria the person met, the more they should be prioritised for this kind of coordinated support. The same principles should be followed with the assignment of a key worker for people with less severe and complex needs.

The committee acknowledged that complex case management can be expensive. Given the lack of evidence about the cost effectiveness of complex case management, 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 accident and emergency (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. 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.

The committee agreed that if the person's single point of contact is going to change when rehabilitation changes or ends, this should be communicated to the person so that they still have a single point of contact even when there is no active rehabilitation plan in place.

The committee made a recommendation for research on the effectiveness and cost

effectiveness of complex case management in the delivery of rehabilitation for people with a chronic neurological disorder to enable provision of more detailed recommendations in this area in the future.

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 manager roles, even for the minority of people with the most complex needs, and so this 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

Information, advice and learning as part of rehabilitation

Recommendations 1.12.1 to 1.12.7

Why the committee made the recommendations

Evidence showed that people with limited understanding of their condition access rehabilitation less. Access to rehabilitation services, social care and other support services were reduced when the person did not receive personalised information. The committee agreed the most important areas for this personalised information to cover.

The committee agreed that people with a functional neurological disorder are less likely to engage in rehabilitation programmes if a diagnosis is not accepted or understood. They set out the requirements for information provision and psychoeducation for this population.

Evidence showed that insufficient financial support to access transport and equipment,

such as wheelchairs, hindered social participation. It also highlighted that applying for government support is often confusing, particularly for people with cognitive symptoms. The committee noted that while funding exists, it is poorly promoted, and application 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, they noted that many people with a chronic neurological disorder and their families are unaware of this right.

Evidence highlighted that information should be accessible and timely and is particularly beneficial when people move between services. 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 when the person's needs change.

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

The committee noted the importance of supporting people to disclose information about their condition and rehabilitation needs in the community and socially, as this can be challenging.

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 people to relevant services.

Return to recommendations

Pain management

Recommendations 1.13.1 to 1.13.5

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 people with a chronic neurological disorder may often persevere with pain or be prescribed analgesia that is ineffective. They recognised that healthcare practitioners can support people with a chronic neurological disorder to better understand and appropriately manage their pain so they can take part in rehabilitation.

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

The committee was aware that NICE's guidelines on chronic and neuropathic pain only cover the adult population and that advice would be needed regarding children and young people.

People with a chronic neurological disorder can present with complex pain issues that may require referral or advice from a pain specialist.

How the recommendations might affect practice

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

Return to recommendations

Fatigue

Recommendations 1.14.1 to 1.14.8

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.

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 specialist advice can be sought, if needed.

Interventions

The committee highlighted that some people with a chronic neurological disorder have difficulty identifying that they have fatigue. They emphasised the importance of understanding, with the person, the causes and impact of fatigue, in order to enable the person to better engage in rehabilitation.

Some people with a chronic neurological disorder may have difficulty expressing that they are experiencing fatigue. Family, carers and other people that are important to the person are therefore critical in highlighting the impact fatigue is having on the person, so that the correct interventions and support can be offered.

Evidence on the effectiveness of specific combinations of physical activity and psychological interventions for managing fatigue was inconsistent. However, energy-conservation strategies, cognitive behavioural therapy and appropriate physical activity (in terms of frequency, intensity and duration) were found to 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 compared 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 having discussions and providing 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 1.15.1 to 1.15.7

Why the committee made the recommendations

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

Problems with executive function, fatigue and pain can be significant barriers to physical activity and so should be taken into account when developing exercise and 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.

People with a functional neurological disorder have specific needs in terms of exercise and physical activity programmes because of the nature of their condition, so the committee

made an additional recommendation for this population.

Having a registered practitioner with the right expertise to develop and oversee the person's exercise and physical activity programme should promote safe and high-quality care.

The committee recognised that other activities could help the person's general physical health. Having a discussion to identify activities they enjoy, including those they can do independently, such as walking, can help ensure the person stays 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 agreed that it is important to talk to the person to identify barriers preventing them achieving their physical activity goals 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

Providing registered practitioners with expertise in exercise programmes and physical health to develop and oversee these programmes may require additional staff and training.

However, this will help ensure the delivery of appropriate care and may reduce risks and potential harms, which can incur substantial costs to the healthcare system.

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 1.16.1 to 1.16.15

Why the committee made the recommendations

Evidence showed that standardised exercises for improving and sustaining stability, mobility and upper limb functioning had some benefits. However, the committee noted that specific and targeted 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 target the person's needs around stability, mobility and both upper and lower 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. However, the committee also highlighted that interventions like serial casting may be harmful for some people, particularly for people with a functional neurological disorder. They agreed that using orthotics, splints or serial or removal casting without careful consideration can worsen symptoms and reinforce unhelpful beliefs.

Evidence showed that using gaming modalities and virtual reality to enhance exercises for stability, mobility and limb functioning 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 found that treadmill gait training improved gait and balance outcomes. It also increased exercise capacity leading to better engagement and participation in other areas of rehabilitation. This aligned with the committee's knowledge and experience. The committee also noted this training can promote long-term participation in physical activity.

Evidence on different frequencies of treadmill training showed that high-frequency training led to 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 these populations.

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 is costly but can be reused. Therapists can monitor several people simultaneously and there is potential to replace expensive traditional machines. Practice varies, but some centres already have this equipment. Overall, this recommendation is not expected to significantly impact resources.

Robotics have high initial costs but can save practitioner 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 shortage

of staff 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 1.17.1 to 1.17.17

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.

The committee also agreed that having a registered mental health practitioner with the required expertise to develop and oversee the emotional health and mental wellbeing element of the person's rehabilitation plan should promote safe and high-quality care.

The committee identified the following issues that need to be recognised when assessing emotional health and mental wellbeing:

- neurological injury can cause neurological disturbance or changes, difficulties with emotional regulation or 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.

The committee agreed that joint neuropsychological assessments are important for understanding cognitive function, emotional health and mental wellbeing, and behaviour, especially when neurobehavioural changes are involved. This approach allows for more targeted evaluations and supports accurate, person-centred care.

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. For example, this impact may be felt intensely by people with a spinal cord injury if wheelchair use affects their interactions with other people and the world. It is also pertinent for people with reduced cognitive abilities or hidden disabilities that prevent them from being as independent as they once were. 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, people important to the person and the person's 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.

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.

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 (for example, music, art or drama) 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.

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.

There was limited evidence for children and young people and 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

Providing a registered mental health practitioner to develop and oversee the emotional health and mental wellbeing element of a person's rehabilitation plan may require

additional staff and training. However, this will help ensure the delivery of appropriate care and may reduce potential harms, which can incur substantial costs to the healthcare system.

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. Where neurorehabilitation services lack expertise in clinical psychology or neuropsychology, additional resources may be needed to enable effective two-way communication between neurorehabilitation and mental health services.

More consistent consideration of emotional health and wellbeing, behaviour and cognitive function may require additional staff and training and increase demand for support services. However, not everyone with a chronic neurological disorder will require such support. This approach may also enable earlier, targeted support, improve outcomes, and potentially reduce overall costs by reducing inappropriate therapy and reliance on crisis care.

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 1.18.1 to 1.18.18

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.

The committee also discussed the importance of repeating cognitive assessments for children and young people to track cognitive development and academic attainment.

Assessment

Having a registered practitioner with expertise in neuropsychology to oversee and interpret cognitive assessments and oversee the cognitive functioning element of the person's rehabilitation plan should promote safe and high-quality care.

The committee agreed that joint neuropsychological assessments are important for understanding cognitive function, emotional health and mental wellbeing, and behaviour, especially when neurobehavioral changes are involved. This approach allows for more targeted evaluations and supports accurate, person-centred care.

The committee agreed that people with suspected cognitive communication disorder need coordinated and interdisciplinary assessments and planning of rehabilitation to ensure they receive the appropriate support.

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 1 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. This is because standard tests in controlled environments, while accurate at detecting cognitive impairments, do not always 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 noted that for people with a functional neurological disorder, dynamic testing and observation may be more useful than standard cognitive tests. Dynamic testing ensures that cognitive function is assessed over time and under varying conditions, rather than relying on a single performance of a standard test. It is, therefore, useful for

assessing inconsistencies in cognitive performance, which is particularly relevant for this population.

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 some people with a chronic neurological disorder sometimes found the content of the assessments tools to be patronising. So, the committee recommended that practitioners should explain what the assessments involve and why they are needed, where possible.

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 reduce the impact of difficulties with executive function, memory and learning on day-to-day activities.

The committee highlighted that based on their knowledge and experience people with executive function deficits often struggle with self-managing their 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 for people with a chronic neurological disorder like multiple sclerosis or 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

Assessing emotional health and mental wellbeing, and behaviour, alongside cognitive function, may require additional staff and training. Providing a registered practitioner with expertise in neuropsychology to oversee and interpret cognitive assessment and oversee the cognitive functioning element of a person's rehabilitation plan may also require extra staff and training. However, these approaches may enable earlier, targeted support, reduce inappropriate therapy and prevent potential harms, all of which incur substantial costs for the healthcare system.

Repeating cognitive assessments in children and young people should reflect standard practice for most services, so no resource impact is anticipated.

Functional assessments are not done in 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.

Dynamic testing and observation for people with a functional neurological disorder may require more practitioner time compared to standard cognitive tests. However, the extra time needed is unlikely to be significant and this approach may help prevent misdiagnosis and unnecessary or inappropriate interventions, potentially offsetting any additional costs.

Return to recommendations

Speech, language and communication

Recommendations 1.19.1 to 1.19.8

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 strengths and 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 important 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 1.20.1 to 1.20.13

Why the committee made the recommendations

Assessment and management

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 (this should be done by a registered practitioner trained in dysphagia).

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.

Some people with a chronic neurological disorder will benefit from food and fluid modifications. 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

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 taking into account 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.

When undertaking risks assessments concerning eating and drinking by mouth, the committee highlighted the importance of considering personal preferences and choice in the context of delivering safe care. It is also important to consider future escalation of risks and needs.

How the recommendations might affect practice

Providing a registered practitioner trained in dysphagia to assess the person's ability to eat, drink and swallow if there are indicators of dysphagia may require additional staff and training. However, this will help ensure the delivery of appropriate care and may reduce potential harms, which can incur substantial costs to the healthcare system. Other recommendations should reflect standard practices for most services, with no resource impact anticipated.

Return to recommendations

Independent living, equipment and environmental adaptations

Recommendations 1.21.1 to 1.21.11

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

Having a registered practitioner to develop and oversee the element of the person's rehabilitation plan concerned with improving or maintaining independence with activities

of daily living should promote safe and high-quality care.

The committee discussed compensatory aids to support activities of daily living. Some found these devices 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 also highlighted that equipment or compensatory aids may be harmful for some people, particularly for people with a functional neurological disorder. They agreed that inappropriate use of equipment can worsen symptoms and reinforce unhelpful beliefs.

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 they are being trained in.

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 through 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

Providing registered practitioners to develop and oversee the element of the person's rehabilitation plan concerned with improving or maintaining independence with activities of daily living may require additional staff and training. However, this will help ensure the delivery of appropriate care and may reduce potential harms, which can incur substantial costs to the healthcare system.

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 1.22.1 to 1.22.6

Why the committee made the recommendations

There was a lack of quantitative evidence on the effectiveness of interventions or approaches for supporting people to remain in, return to or leave education and training. So, instead the committee made recommendations based on their expertise and qualitative evidence.

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 prognoses are determined and rehabilitation needs are identified. They should also agree the equipment, adaptations and adjustments necessary to meet the child or young person'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 in 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 stage changes. 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 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 1.23.1 to 1.23.9

Why the committee made the recommendations

There was a lack of quantitative evidence on the effectiveness of interventions or approaches for supporting people to enter, remain in or leave employment and volunteering. So, instead the committee made recommendations based on their expertise and qualitative evidence.

The committee agreed 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, where this follows the wishes of the person. This can help to identify support needs and set expectations. The committee highlighted the importance of identifying and addressing any potential barriers for return to work, as well as collaborating with other professionals in the workplace in order to access support.

The committee agreed that the detailed guidance on managing return-to-work in NICE's guideline on stroke rehabilitation in adults was applicable to the populations covered in this guideline.

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

Evidence showed that although there were benefits to educating employers about chronic neurological disorders, people with these disorders 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 in which 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 these 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 arise.

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 to help inform future recommendations in this area.

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 healthcare practitioners and education services are

often through email, and fewer face-to-face meetings could be more efficient. Free e-learning modules on partnership working and resources for GPs and employers are available to support collaborative working.

Return to recommendations

Participating in social and leisure activities

Recommendations 1.24.1 to 1.24.7

Why the committee made the recommendations

There was a lack of quantitative evidence on the effectiveness of interventions or approaches for supporting participation in social and leisure activities. So, instead the committee made recommendations based on their expertise and qualitative evidence.

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 activities and that this is made worse if they have cognitive difficulties. They agreed that GPs often provide this support but noted that any healthcare or social care practitioners could do this.

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

People with a chronic neurological disorder can find it challenging and emotional to discuss their condition and what adjustments and adaptations they need. 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. Staff may need training to ensure they are well-informed and can provide appropriate signposting.

Community services 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. Interventions to promote social participation are therefore likely to represent value for money.

Return to recommendations

Family life and friendships

Recommendations 1.25.1 to 1.25.3

Why the committee made the recommendations

There was a lack of quantitative evidence on the effectiveness of interventions or approaches for supporting family life and friendships. So, instead the committee made recommendations based on their expertise and qualitative evidence.

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 relationships 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 1.26.1 to 1.26.11

Why the committee made the recommendations

There was a lack of quantitative evidence on the effectiveness of interventions or approaches for supporting intimate and sexual relationships. So, instead the committee made recommendations based on their expertise and qualitative evidence.

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 about leading these discussions.

Evidence highlighted a lack of knowledge among healthcare practitioners about sexual rehabilitation and intimacy, 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 they should know when and how to signpost to appropriate services.

The committee agreed that the topic of intimacy and sexual relationships 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, sex and sexual functioning 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 long-term, often life-long consequences of neurological disease and disorders. Rehabilitation needs may be progressive or fluctuating. 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. These are:

- progressive neurological disease
- acquired brain injury
- acquired spinal cord injury
- acquired peripheral nerve disorder
- functional neurological disorder.

For a detailed list of the diseases, disorders and injuries that are included and excluded see the section on inclusions and exclusions.

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, and activity or participation approaches focused on 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.

Inclusions and exclusions

Inclusions

Note there may be diseases, disorders and injuries that are not included in these lists but where the resulting neurological impairment or disabling neurological symptoms would still be covered by this guideline.

Progressive neurological disease

Disorders that involve a gradual progression of neurological difficulties over time. This includes congenital disorders that result in long-term chronic neurological disorders, impairment and symptoms and where there is a progressive need for neurorehabilitation (for example, as children grow).

- Parkinson-plus syndrome
- Parkinson's disease
- progressive supranuclear palsy
- corticobasal degeneration
- multiple sclerosis
- multiple system atrophy
- motor neurone disease:
  - amyotrophic lateral sclerosis (also known as Lou Gehrig's disease and Charcot's disease)
  - primary lateral sclerosis
  - progressive muscular atrophy
  - progressive bulbar palsy
  - Kennedy's disease (also known as progressive spinobulbar muscular atrophy)

  - Post-Polio Syndrome
  - spinal muscular atrophy
- muscular dystrophy, for example, Duchenne muscular dystrophy
- Friedreich's ataxia
- Huntington's disease
- Batten disease
- white matter disorders, for example, metachromatic leukodystrophy
- mitochondrial myopathy
- mucopolysaccharidosis (lysosomal storage disorders)
- primary dystonia
- spina bifida
- other genetic disorders, for example, Williams syndrome, catch 22 disease, Rett syndrome, hereditary spastic paraplegia, hereditary motor neuropathy and hereditary sensory autonomic neuropathy.

Acquired brain injury

Injuries to the brain that result in neurological impairment. Possible causes covered by this guideline are:

- tumours
- traumatic injury, including shaken baby syndrome
- chronic encephalitis
- chronic hydrocephalus
- hypoxic brain injury, including near drowning
- chronic and persistent neurological symptoms as a result of infection:
  - viral causes, for example, polio and AIDS

  - bacterial causes, for example, neuro-syphilis and tuberculosis
- alcohol or drug induced brain injury
- stroke in under-16s.

Acquired spinal cord injury

Injuries to the spinal cord that result in neurological impairment. Possible causes are:

- tumours
- traumatic injury
- chronic and persistent neurological symptoms as a result of infection:
  - viral causes, for example, polio and AIDS
  - bacterial causes, for example, neuro-syphilis and tuberculosis
- vascular infarction or haemorrhage (including arteriovenous malformation bleed)
- transverse myelitis.

Acquired peripheral nerve disorder

Acute-onset disorders of the peripheral nervous system that result in neurological impairment. Causes may be inflammatory, autoimmune or paraneoplastic:

- inflammatory-related causes, for example, chronic inflammatory demyelinating neuropathy
- alcohol induced nerve disorders
- diabetic neuropathy
- motor or sensory neuropathy
- Guillain-Barre syndrome
- autoimmune-related causes:
  - for example, multi focal motor neuropathy, Lupus and Sjögren's syndrome

  - from infections, for example, chicken pox, West Nile, herpes, Lyme disease and HIV

- paraneoplastic-related causes, for example, from tumour or neoplasm.

Functional neurological disorder

A disorder causing 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. Also sometimes referred to as:

- functional neurological symptom disorder
- functional movement disorder
- conversion disorder
- cognitive dysfunction
- psychogenic seizures
- movement disorder
- dissociative seizures
- motor disorder
- non-epileptic seizures.

Exclusions

- Stroke in overs 16s. See NICE's guideline on stroke rehabilitation in adults.
- Cerebral palsy. See NICE's guidelines on cerebral palsy in adults and cerebral palsy in under 25s.
- Dementia (including Alzheimer's disease). See NICE's guideline on dementia.
- Myalgic encephalomyelitis (or encephalopathy) / chronic fatigue syndrome. See NICE's guideline on myalgic encephalomyelitis (or encephalopathy) / chronic fatigue syndrome.

- Epilepsy. See NICE's guideline on epilepsies in children, young people and adults.

This guideline does not cover disorders for which interventions are primarily focused on altering body structure and functions, for example, isolated peripheral nerve injury (single nerve or plexus injury) or autonomic neuropathy, where management is primarily non-rehabilitation.

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 full details of the evidence and the guideline committee's discussions, see the evidence reviews. You can also find information about how the guideline was developed, including details of the committee.

NICE has produced tools and resources to help you put this guideline into practice. For general help and advice on putting our guidelines into practice, see resources to help you put NICE guidance into practice.

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