

Package of Interventions for Rehabilitation

Interventions for Cerebral palsy

Identified from Clinical Practice Guidelines

Rehabilitation domains*

	Rehabilitation Domains	N of identified interventions
B	Interventions for Mental functions	10
C	Interventions for Vision impairment	3
D	Interventions for Hearing impairment	2
E	Interventions for Speech, Language and Communication	6
F	Interventions for Dysphagia management	8
G	Interventions for Nutrition	2
H	Interventions for Pain management	4
I	Interventions for Bowel and Bladder management and Toileting	1
J	Interventions for Sexual functions and intimate relationships	3
K	Interventions for Respiration functions	8
L	Interventions for Skin care	1
M	Interventions for Cardiovascular and hematological functions	-
N	Interventions for Motor functions and Mobility	60
O	Interventions for Activities of daily living	5
P	Interventions for Exercise and Fitness	1
Q	Interventions for Fall prevention	-
R	Interventions for Interactions and Relationships	3
S	Interventions for Education and Vocation	1
T	Interventions for Community and social life	5
U	Interventions for Carer/Family support	-
V	Interventions for Self-management	4
W	Interventions for Lifestyle modifications	-

*Please note: This list is not exhaustive and might be supplemented by more domains along the development of the Package of Rehabilitation Interventions.

For domains marked in blue letters, interventions have been identified for Ischemic heart disease. "Interventions" also include "assessments".

Included guidelines

Title of the guideline	Short title	Target population	Topic of the guideline
NICE Guideline NG 119: Cerebral palsy in adults; published 2019	NICE_Ad	Adults with CP >18	This guideline covers care and support for adults with cerebral palsy. It aims to improve health and wellbeing, promote access to services and support participation and independent living
NICE Guideline NG 62: Cerebral palsy in under 25s: assessment and management; published 2017	NICE_25	Children and young people from birth - ≤ 25	This guideline covers diagnosing, assessing and managing cerebral palsy. It aims to make sure they get the care and treatment they need for the developmental and clinical comorbidities associated with cerebral palsy, so that they can be as active and independent as possible.
NICE Guideline CG 145: Spasticity in under 19s: management; published 2012	NICE_19	Children and young people (from birth - <19) with non-progressive brain disorders	Management of spasticity and co-existing motor disorders and their early musculoskeletal complications
Love SC et al.: Botulinum toxin assessment, intervention and after-care for lower limb spasticity in children with cerebral palsy: international consensus statement. Eur J Neurol 2010; 17 (Suppl. 2): 9-37	Love	People with spasticity caused by CP ≤18	Use of Botulinum neurotoxin type-A (BoNT-A) in the management of spasticity in children with cerebral palsy (CP)
AACPDM Care Pathway: Dystonia - Bottom Line 'Evidence-Informed' Recommendations for the Management of Dystonia in Individuals with Cerebral Palsy	DYST	Individuals at all ages with dystonia in CP where the dystonia interferes with function, positioning or causes pain and disrupted sleep.	Assessment and management of dystonia in individuals with CP
AACPDM Care Pathway: Osteoporosis - Bottom Line 'Evidence-Informed' Recommendations for Children/Youth with Cerebral Palsy who are Non-Ambulatory and at risk for or have Osteoporosis; published 2016	OSTEO	Children/youth with CP who are non-ambulatory and at risk for or have osteoporosis	Prevention and treatment of osteoporosis and fragility fractures in children and youth with CP

Classification of the Strength of recommendation

	NICE guidelines (NICE)	Love	DYSTONIA AND OSTEOPOROSIS CARE PATHWAY
Note:	The wording used in each recommendation is proxy for the strength of the guideline. Recommendations from 2007 are not based on strength of the recommendation, thus their wording should not be interpreted to denote strength.	All recommendations were graded based on the American Academy of Neurology evidence classification [American Academy of Neurology. AAN classification of evidence for therapeutic intervention. 2004.].	Wording is used to provide information on the strength of recommendation.
STRONG	Strong: Words such as 'must' or 'must-not' are for recommendations that legally must be applied, whereas words like 'offer', 'refer' and 'advise' are to denote strong recommendation.	A: Rating requires at least two consistent Class I studies. Established as effective, ineffective or harmful (or established as useful/ predictive or not useful/ predictive) for the given condition in the specified population B: Rating requires at least one Class I study or two consistent Class II studies. Probably effective, ineffective or harmful (or probably useful/predictive or not useful/predictive) for the given condition in the specified population	A: Must (not) prescribe, offer (Rx) Must (not) test, counsel, monitor (Scrn, Dx, Px) Must avoid (causation) B: Should (not) offer, prescribe Should (not) test, counsel, monitor Should avoid
WEAK/CONDITIONAL	Weak: Recommendations that are expected to do more good than harm for most people, but need to be considered by the healthcare provider on a case-to-case basis, use the word 'consider'.	C: Rating requires at least one Class II study or two consistent Class III studies. Possibly effective, ineffective or harmful (or possibly useful/predictive or not useful/predictive) for the given condition in the specified population	C May offer, prescribe May test, counsel, monitor, educate May avoid May choose not to offer, prescribe May choose not to test
EXPERT OPINION		U: Studies not meeting criteria for Class I – Class III Data inadequate or conflicting. Given current knowledge, treatment (test, predictor) is unproven. Recommendation based on expert opinion)	U: Recommendation based on expert opinion)

Classification of the Quality of the evidence

	NICE guidelines 2013 (NICE)	Love BT	DYSTONIA AND OSTEOPOROSIS CARE PATHWAY
Note:	GRADE approach was used to evaluate the quality of each single study. The overall quality of the evidence is provided by an evaluation of all included evidence.		Full text of classification system is available at: AAN (American Academy of Neurology). 2011. <i>Clinical Practice Guideline Process Manual</i> , 2011 Ed. St. Paul, MN: The American Academy of Neurology.
High	High Further research is very unlikely to change our confidence in the estimate of effect.	Class I Prospective, randomized, controlled clinical trial with masked outcome assessment, in a representative population. a) primary outcome(s) clearly defined b) exclusion/inclusion criteria clearly defined c) adequate accounting for drop-outs and cross-overs with numbers sufficiently low to have minimal potential for bias d) relevant baseline characteristics are presented and substantially equivalent among treatment groups or there is appropriate statistical	Class I Randomized, controlled clinical trial (RCT) in a representative population - Masked or objective outcome assessment - Relevant baseline characteristics are presented and substantially equivalent between treatment groups, or there is appropriate statistical adjustment for differences
Moderate	Moderate Further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate.	Class II Prospective matched group cohort study in a representative population with masked outcome assessment that meets a-d above OR a RCT in a representative population that lacks one criteria a-d.	Class II - Cohort study meeting criteria a-e (see Class I) or an RCT that lacks one or two criteria b-e (see Class I) - All relevant baseline characteristics are presented and substantially equivalent among treatment groups or there is appropriate statistical adjustment for differences - Masked or objective outcome assessment
Low	Low Further research is very likely to have an important impact on our confidence in the estimate of effect and is likely to change the estimate.	Class III All other controlled trials (including well-defined natural history controls or patients serving as own controls) in a representative population, where outcome is independently assessed, or independently derived by objective outcome measurement.	Class III - Controlled studies (including well-defined natural history controls or patients serving as their own controls) - A description of major confounding differences between treatment groups that could affect outcome** - Outcome assessment masked, objective or performed by someone who is not a member of the treatment team.
Very Low	Very low Any estimate of effect is very uncertain.	Class IV Evidence from uncontrolled studies, case series, case reports, or expert opinion.	Class IV - Did not include patients with the disease - Did not include patients receiving different interventions - Undefined or unaccepted interventions or outcome measures - No measures of effectiveness or statistical precision presented or calculable

B) Rehabilitation interventions for mental functions

N°	Intervention	Original recommendation	Specification of target population	SoR	QoE	Ref.
PSYCHIC STABILITY						
B1	Assessment	At every review, explore with the adult with cerebral palsy (and their family and carers, if agreed) if they have any concerns about, for example, their mood; irritability ; behaviour; social interaction sleep; general level of function.	Adults	Strong	Expert opinion	NICE_Ad: Page 22; 4.12
EMOTIONAL FUNCTIONS						
B2	Assessment	Assess for other possible causes of distress in the absence of identifiable physical causes of pain and discomfort, such as: psychological and emotional distress, increased sensitivity to environmental triggers, thirst or hunger.	Children and young people under 25:	Strong	n.a.	NICE_25: Page 307; 21.6. Rec. 92
		Always ask about pain, sleep and distress as part of any clinical consultation.	Children and young people under 25:	Strong	n.a.	NICE_25: Page 307; 20.6. Rec. 95
		Discuss with the adult with cerebral palsy (and their family and carers, if agreed) if physical problems, such as pain, or frustration from communication difficulties or lack of stimulation are contributing to emotional distress or challenging behaviour .	Adults	Strong	Expert opinion	NICE_Ad: Page 23; 4.15
		Refer the child or young person for a specialist multidisciplinary team assessment of pain, discomfort, distress and sleep if the cause of these is not clear after routine assessment.	Children and young people under 25:	Strong	n.a.	NICE_25: Page 306; 21.6. Rec. 89
INTELLECTUAL FUNCTIONS						
B3	Education and counselling	Explain to children and young people with cerebral palsy and their parents or carers that difficulties with learning and movement may be exacerbated by difficulties with registering or processing sensory information, which can affect function and participation. Sensory difficulties may include: primary sensory disorders in any of the sensory systems, such as processing of visual or auditory information (for example, difficulties with depth perception may affect the ability to walk on stairs); disorders of sensory processing and perception, such as planning movements or being able to concentrate and pay attention.	Children and young people under 25:	Strong	Very low to moderate	NICE_25: Page 358; 26.7. Rec. 117
		Talk to children and young people and their parents or carers about learning disability (intellectual disability) that can be associated with cerebral palsy (for example, problems with knowledge acquisition, memory, and understanding and use of language). Information that may be useful to discuss includes the following: learning disability (IQ below 70) occurs in around 1 in 2 children and young people with cerebral palsy; severe learning disability (IQ below 50) occurs in around 1 in 4 children and young people with cerebral palsy; learning disability can be associated with any functional level, but prevalence increases with increasing severity of motor impairment: GMFCS level I or II: around 1 in 3 have an IQ below 70; GMFCS level III, IV or V: around 2 in 3 have an IQ below 70.	Children and young people under 25:	Strong	Low to high	NICE_25: Page 386; 27.20. Rec.131

MENTAL HEALTH						
B4	Assessment	Use validated tools, such as the Child Health Questionnaire and the Strengths and Difficulties Questionnaire, to assess mental health problems in children and young people with cerebral palsy.	Children and young people under 25:	Strong	n.a.	NICE_24: Page 334; 24.6. Rec. 112
		Ask adults with cerebral palsy what they enjoy doing and if they find it difficult to participate in a chosen activity, assess their physical and mental health , and address any factors identified that may be affecting participation, if possible.	Adults	Strong	Expert opinion	NICE_Ad: Page 11; 2.8
		Identify and address mental health problems alongside physical health problems. Recognise that the impact of mental health problems and emotional difficulties can be as important as physical health problems for adults with cerebral palsy.	Adults	Strong	Expert opinion	NICE_Ad: Page 22; 4.9
		Refer the child or young person with cerebral palsy for specialist psychological assessment and ongoing management if emotional and behavioural difficulties persist or there are concerns about their mental health.	Children and young people under 25:	Strong	Very low to low	NICE_25: Page 345; 25.7. Rec. 113
B5	Carer support	When making an individual management plan to address the mental health needs of a child or young person with cerebral palsy, take into account ways of providing support to parents or carers .	Children and young people under 25:	Strong	Very low to low	NICE_25: Page 345; 25.7. Rec.115
SLEEP FUNCTIONS						
B6	Assessment	Always ask about pain, sleep and distress as part of any clinical consultation.	Children and young people under 25:	Strong	n.a.	NICE_25: Page 307; 20.6. Rec.95
		At every review, explore with the adult with cerebral palsy (and their family and carers, if agreed) if they have any concerns about, for example, their: mood; irritability; behaviour; social interaction sleep; general level of function.	Adults	Strong	Expert opinion	NICE_Ad: Page 22; 4.12
		Assess the impact of the dystonia on function, pain/comfort (including sleep), and caregiving and whether management is required.			Not specified	DYST: page 1
		Refer the child or young person to specialist sleep services for multidisciplinary team assessment and management if there are ongoing sleep disturbances .	Children and young people under 25:	Strong	Low to high	NICE_25: Page 322; 23.7. Rec. 105
		Refer the child or young person for a specialist multidisciplinary team assessment of pain, discomfort, distress and sleep if the cause of these is not clear after routine assessment.	Children and young people under 25:	Strong	n.a.	NICE_25: Page 306; 21.6. Rec. 89

B7	Pharmacological treatment	Do not offer regular sedative medication to manage primary sleep disorders in children with cerebral palsy without seeking specialist advice.	Children and young people under 25	Strong against	Low to high	NICE_25: Page 322; 23.7. Rec.103
		If no treatable cause is found, consider a trial of melatonin[7] to manage sleep disturbances for children and young people with cerebral palsy, particularly for problems with falling asleep.	Children and young people under 25	Conditional	Low to high	NICE_25: Page 322; 23.7. Rec. 102
B8	Sleep hygiene	Optimise sleep hygiene for children and young people with cerebral palsy.	Children and young people under 25	Strong	Low to high	NICE_25: Page 322; 23.7. Rec. 100
B9	Sleep positioning system	Do not offer sleep positioning systems solely to manage primary sleep disorders in children and young people with cerebral palsy.	Children and young people under 25	Strong against	Low to high	NICE_25: Page 322; 23.7. Rec. 104
B10	Education and counselling	Explain to parents or carers that, in children and young people with cerebral palsy, sleep disturbances (for example, difficulties with falling asleep, staying asleep or daytime sleepiness): are common; may be caused by factors such as environment, hunger and thirst.	Children and young people under 25	Strong	Very low to moderate	NICE_25: Page 299; 20.6. Rec. 86

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C) Interventions for Vision impairment

N°	Intervention	Original recommendation	Specification of target population	SoR	QoE	Ref.
SEEING FUNCTIONS						
C1	Assessment	Regularly assess children and young people with cerebral palsy for signs of cerebral visual impairment , bearing in mind that this: occurs in around 1 in 5 children and young people with cerebral palsy; may occur in children and young people with any functional level or motor subtype, but prevalence increases with increasing severity of motor impairment; may be difficult to recognise in the early stages.	Children and young people under 25	Strong	Low to moderate	NICE_25: Page 386; 27.20. Rec. 129
C2	Referral to specialist	Refer all children with cerebral palsy for an initial baseline ophthalmological and orthoptic assessment at the time of diagnosis.	Children and young people under 25	Strong		NICE_25: Page 385; 27.20. Rec. 125
		If concerns about visual impairment are raised by parents, carers or members of the care team, consider referring the child or young person with cerebral palsy to a specialist team for evaluation of the whole visual system (including eye health, eye movements, refraction, squint and visual acuity), especially if there are communication difficulties.	Children and young people under 25	Conditional	Low to moderate	NICE_25: Page 386; 27.20. Rec. 128
C3	Education and counselling	Talk to children and young people and their parents or carers about visual impairment that can be associated with cerebral palsy. Information that may be useful to discuss includes the following: around 1 in 2 children and young people with cerebral palsy will have some form of visual impairment; visual impairment may occur in children and young people with any functional level or motor subtype, but prevalence increases with increasing severity of motor impairment.	Children and young people under 25	Strong	Low to moderate	NICE_25: Page 385; 27.20. Rec. 126
		Talk to children and young people and their parents or carers about the different types of visual impairment that can be associated with cerebral palsy. Explain that these could include 1 or more of the following: problems with controlling eye movements; strabismus (squint); refractive errors (short or long sighted or distorted image); problems of eye function, including retinopathy of prematurity; impaired cerebral visual information processing (problems with seeing objects caused by damage to the parts of the brain that control vision); visual field defects (loss of the part of usual field of vision).	Children and young people under 25	Strong	Low to moderate	NICE_25: Page 385; 27.20. Rec. 127

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D) Interventions for Hearing impairment

N°	Intervention	Original recommendation	Specification of target population	SoR	QoE	Ref.
HEARING FUNCTIONS						
D1	Assessment	At every review, ask adults with cerebral palsy (and their families and carers, if agreed) about any changes in their hearing , speech and communication	Adults	Strong	Expert opinion	NICE_Ad: Page 10; Rec. 2.2
D2	Education and counseling	Talk to children and young people and their parents or carers about hearing impairment that can be associated with cerebral palsy. Information that may be useful to discuss includes the following: hearing impairment occurs in around 1 in 10 children and young people with cerebral palsy; it may occur in children and young people with any functional level or motor subtype, but prevalence increases with increasing severity of motor impairment; it is more common in people with dyskinetic or ataxic cerebral palsy than in those with spastic cerebral palsy; regular ongoing hearing assessment is necessary.	Children and young people under 25	Strong	Low to high	NICE_25: Page 386; 27.20. Rec. 130

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E) Rehabilitation interventions for Speech, Language and Communication

N°	Intervention	Original recommendation	Specification of target population	SoR	QoE	Ref.
SPEECH AND LANGUAGE						
E1	Assessment	Regularly assess children and young people with cerebral palsy during routine reviews to identify concerns about speech, language and communication, including speech intelligibility .	Children and young people under 25	Strong	Very low	NICE_25: Page 237; 15.6. Rec. 58
		Refer children and young people with cerebral palsy for specialist assessment if there are concerns about speech, language and communication, including speech intelligibility .	Children and young people under 25	Strong	Very low	NICE_25: Page 237; 15.6. Rec. 59
		At every review, ask adults with cerebral palsy (and their families and carers, if agreed) about any changes in their hearing, speech and communication	Adults	Strong	Expert opinion	NICE_Ad: Page 10; Rec. 2.2
E2	Speech and language therapy	Offer interventions to improve speech intelligibility , for example targeting posture, breath control, voice production and rate of speech, to children and young people with cerebral palsy: who have a motor speech disorder and some intelligible speech and for whom speech is the primary means of communication and who can engage with the intervention.	Children and young people under 25 who have a motor speech disorder	strong	Very low	NICE_25: Page 237; 15.6. Rec. 62
		Refer adults with cerebral palsy who have communication difficulties to speech and language therapy services to assess their need for intervention, which may include: use of alternative or augmentative communication systems; intensive speech therapy to improve the intelligibility of their speech .	Adults	Strong	Very low	NICE_Ad: Page 10; Rec. 2.6
COMMUNICATION						
E3	Assessment	Regularly assess children and young people with cerebral palsy during routine reviews to identify concerns about speech, language and communication , including speech intelligibility.	Children and young people under 25	Strong	Very low	NICE_25: Page 237; 15.6. Rec. 58
		At every review, ask adults with cerebral palsy (and their families and carers, if agreed) about any changes in their hearing, speech and communication	Adults	Strong	Expert opinion	NICE_Ad: Page 10; Rec. 2.2
		Explore with the person with cerebral palsy who has communication difficulties whether they have a potential need for alternative and augmentative communication systems.	Adults	Strong	Expert opinion	NICE_Ad: Page 10; Rec. 2.3
		Regularly review children and young people who are using augmentative and alternative communication systems , to monitor their progress and ensure that interventions continue to be appropriate for their needs.	Children and young people under 25 who are using augmentative and alternative communi-	Strong	Very low	NICE_25: Page 247; 16.7. Rec. 65

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		Refer children and young people with cerebral palsy for specialist assessment if there are concerns about speech, language and communication , including speech intelligibility.	Children and young people under 25	Strong	Very low	NICE_25: Page 237; 15.6. Rec. 59
E4	Alternative and augmentative communication systems	If there are ongoing problems with using augmentative and alternative communication systems, refer the child or young person to a specialist service in order to tailor interventions to their individual needs, taking account of their cognitive, linguistic, motor, hearing and visual abilities.	Children and young people under 25	Strong	Very low	NICE_25: Page 247; 16.7. Rec. 64
		Consider augmentative and alternative communication systems for children and young people with cerebral palsy who need support in understanding and producing speech. These may include pictures, objects, symbols and signs, and speech generating devices.	Children and young people under 25	Conditional	Very low	NICE_25: Page 247; 16.7. Rec. 63
		Refer adults with cerebral palsy who have communication difficulties to speech and language therapy services to assess their need for intervention, which may include: use of alternative or augmentative communication systems ; intensive speech therapy to improve the intelligibility of their speech.	Adults	Strong	Very low	NICE_Ad: Page 10; Rec. 2.6
		Ensure that training is provided for people with cerebral palsy using alternative and augmentative communication systems and their families, carers and other key communication partners in home, care, social or work environments.	Adults	Strong	Expert opinion	NICE_Ad: Page 10; Rec. 2.4
E5	Communication training for family members and care providers	Provide individualised training in communication techniques for families, carers, pre-school and school staff and other people involved in the care of a child or young person with cerebral palsy.	Children and young people under 25: Families, carers, pre-school and school staff and other people involved in the care	Strong	Very low	NICE_25: Page 247; 16.7. Rec. 66
E6	Education and counseling	Talk to children and young people and their parents or carers about communication difficulties that can be associated with cerebral palsy. Information that may be useful to discuss includes the following: communication difficulties occur in around 1 in 2 children and young people with cerebral palsy; at least 1 in 10 need augmentative and alternative communication (signs, symbols and speech generating devices); around 1 in 10 cannot use formal methods of augmentative and alternative communication because of cognitive and sensory impairments and communication difficulties; communication difficulties may occur with any functional level or motor subtype, but are more common in children and young people with dyskinetic or severe bilateral spastic cerebral palsy; communication difficulties do not necessarily correlate with learning disability (intellectual disability).	Children and young people under 25	Strong	Very low, high	NICE_25: Page 387; 27.20. Rec. 132

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F) Interventions for Ingestion and Dysphagia management

N°	Intervention	Original recommendation	Specification of target population	SoR	QoE	Ref.
SALIVATION						
F1	Assessment	Assess factors that may affect drooling in children and young people with cerebral palsy, such as positioning, medication history, reflux and dental issues, before starting drug therapy.	Children and young people under 25	Strong	Very low to moderate	NICE_25: Page 265; 17.7. Rec. 67
		Regularly review the effectiveness, tolerability and side effects of all drug treatments used for saliva control.	Children and young people under 25	Strong	Very low to moderate	NICE_25: Page 265; 17.7. Rec. 69
F2	Anticholinergic medication	To reduce the severity and frequency of drooling in children and young people with cerebral palsy, consider the use of anticholinergic medication : glycopyrronium bromide[3] (oral or by enteral tube) or transdermal hyoscine hydrobromide[4] or trihexyphenidyl hydrochloride[5] for children with dyskinetic cerebral palsy, but only with input from specialist services. When choosing which medicine to use, take into account the preferences of the child or young person and their parents or carers, and the age range and indication covered by the marketing authorisations.	Children and young people under 25	Conditional	Very low to moderate	NICE_25: Page 265; 17.7. Rec. 68
F3	Botulinum toxin injection	Consider specialist assessment and use of botulinum toxin A injections[6] to the salivary glands with ultrasound guidance to reduce the severity and frequency of drooling in children and young people with cerebral palsy if anticholinergic drugs provide insufficient benefit or are not tolerated.	Children and young people under 25 if anticholinergic drugs provide insufficient benefit or are not tolerated.	Conditional	Very low to moderate	NICE_25: Page 266; 17.7. Rec. 71

Cochrane Systematic Review: Walshe M et al. 2012; Interventions for drooling in children with cerebral palsy.

N of included studies (total participants): 6 (198)

Population: Children with cerebral palsy

Setting: Inpatients, outpatients, unknown

Note: Studies were grouped according to the different outcome measures that have been used.

Intervention	Control	Outcome	No of studies	No of participants	Corresponding risk (95% CI)	Quality of evidence (GRADE)	Statistical method	Heterogeneity
BoNT-A	Placebo	Reduction in frequency and severity of drooling (baseline)	1	13	SMD = -0.80	Low	Standardized mean difference	NA
	No intervention	Reduction in frequency and severity of drooling	1	31	SMD = 2.04	Low		NA

	Placebo	Reduction in frequency and severity of drooling (2 weeks)	1	13	SMD = 1.21	Low	NA
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F4	Education and counseling	Advise children and young people and their parents or carers that high-dose botulinum toxin A injection[6] to the salivary glands can rarely cause swallowing difficulties, and so they should return to hospital immediately if breathing or swallowing difficulties occur.	Children and young people under 25	Strong	Very low to moderate	NICE_25: Page 266; 17.7. Rec. 72
SWALLOWING						
F5	Assessment	Refer adults with cerebral palsy and recurrent chest infections, if dysphagia is suspected, to a speech and language therapist with training in dysphagia to assess swallowing .	Adults with recurrent chest infections, if dysphagia is suspected	Strong	Expert opinion	NICE_Ad: Page 26; 4.29
		Use outcome measures important to the child or young person and their parents or carers to review: whether individualised goals have been achieved ; the clinical and functional impact of interventions to improve eating, drinking and swallowing .	Children and young people under 25	Strong	Very low to low	NICE_25: Page 212; 13.7. Rec. 53
		Refer the child or young person to a local specialist multidisciplinary team with training in assessing and treating dysphagia if there are clinical concerns about eating, drinking and swallowing, such as: coughing, choking, gagging, altered breathing pattern or change in colour while eating or drinking; recurrent chest infection; mealtimes regularly being stressful or distressing for the child or young person ; prolonged meal duration.	Children and young people under 25	Strong	Very low to low	NICE_25: Page 189; 12.6. Rec. 44
F6	Assessment: Videofluoroscopy	The specialist multidisciplinary team should consider videofluoroscopy if any of the following apply: There is uncertainty about the safety of eating, drinking and swallowing after specialist clinical assessment; The child or young person has recurrent chest infection without overt clinical signs of aspiration; deterioration in eating, drinking and swallowing ability with increasing age (particularly after adolescence); uncertainty about the impact of modifying food textures (for example, use of thickeners or pureeing); Parents or carers need support to understand eating, drinking and swallowing difficulties, to help with decision-making.	Children and young people under 25	Conditional	Very low to low	NICE_25: Page 189; 12.6. Rec. 46
		Do not use videofluoroscopy or fibroscopic endoscopy for the initial assessment of eating, drinking and swallowing difficulties in children and young people with cerebral palsy.	Children and young people under 25	Strong against	Very low to low	NICE_25: Page 189; 12.6. Rec. 45
		Do not routinely perform videofluoroscopy when considering starting enteral tube feeding in children and young people with cerebral palsy.	Children and young people under 25	Strong against	Very low to low	NICE_25: Page 189; 12.6. Re. 48
F7	Education and counseling	Develop strategies and goals in partnership with the child or young person with cerebral palsy and their parents, carers and other family members for interventions to improve eating, drinking and swallowing .	Children and young people under 25	Strong	Very low to low	NICE_25: Page 211; 13.7. Rec. 50
		Advise parents or carers that intra-oral devices have not been shown to improve eating, drinking and swallowing in children and young people with cerebral palsy.	Children and young people under 25	Strong	Very low to low	NICE_25: Page 211; 13.7.

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VOMITING REGURGITATION						
F8	Education and counseling	Advise parents or carers that vomiting, regurgitation and gastro-oesophageal reflux are common in children and young people with cerebral palsy. If there is a marked change in the pattern of vomiting, assess for a clinical cause.	Children and young people under 25	Strong	Very low	NICE_25: Page 387; 27.20. Rec.137

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G) Interventions for Nutrition

N°	Intervention	Original recommendation	Specification of target population	SoR	QoE	Ref.
PREVENTION OF MALNUTRITION						
G1	Assessment	Discuss if any of the following factors might be affecting the person's appetite, eating habits or weight: changes in carer support; depression; pain; reduced physical activity; side effects of medications.	Adults	Strong	Expert opinion	NICE_Ad: Page 24; 4.18
		Regularly review the nutritional status of children and young people with cerebral palsy, including measuring their height and weight (or consider alternative anthropometric measurements, particularly if height and weight cannot be measured).	Children and young people under 25	Strong	Very low to low	NICE_25: Page 221; 14.7. Rec. 54
		Offer adults with cerebral palsy a regular weight check, and BMI or another anthropometric measurement, and identify people who may be at risk of undernutrition or obesity (see also the NICE guideline on obesity: identification, assessment and management).	Adults	Strong	Expert opinion	NICE_Ad: Page 23; 4.16
		At every review, discuss with adults with cerebral palsy (and their family and Cerebral palsy in adults carers, if agreed) whether they have difficulties with eating or if there have been any changes in their eating habits or bowel function. Ask about issues including: changes in appetite; changes in the person's ability to feed themselves; constipation; coughing or choking when eating; food refusal; increased frequency of chest infections (which may be related to swallowing; difficulties or gastro-oesophageal reflux); an increase in the length of meal times.	Adults	Strong	Expert opinion	NICE_Ad: Page 23; 4.17
		Discuss if any of the following factors might be affecting the person's appetite, eating habits or weight: changes in carer support; depression; pain; reduced physical activity; side effects of medications.	Adults	Strong	Expert opinion	NICE_Ad: Page 24; 4.18
G2	Enteral tube feeding	If oral intake is still insufficient to provide adequate nutrition after assessment and nutritional interventions, refer the child or young person to be assessed for enteral tube feeding by a multidisciplinary team with relevant expertise.	Children and young people under 25 if oral intake is still insufficient to provide adequate nutrition	Strong	Very low to low	NICE_25: Page 221; 14.7. Rec. 56

NOTES:

H) Interventions for Pain management

N°	Intervention	Original recommendation	Specification of target population	SoR	QoE	Ref.
Sensation of pain						
H1	Assessment	Always ask about pain , sleep and distress as part of any clinical consultation.	Children and young people under 25	Strong	n.a.	NICE_25: Page 307; 20.6. Rec. 95
		Assess for the presence, severity and location of pain in adults with cerebral palsy using pain assessment tools such as: numerical rating scales; visual analogue scales; faces pain scales; body maps.	Adults	Strong	Low to moderate	NICE_Ad: Page 28; 4.37
		Consider using tools to identify pain or assess severity of pain in children and young people with cerebral palsy; for example: For children and young people with communication difficulties: Paediatric Pain Profile, Non-communicating Children's Pain Checklist – postoperative version; For children and young people without communication difficulties: Numeric pain rating scale.	Children and young people under 25	Conditional	n.a.	NICE_25: Page 307; 21.6. Rec. 93
		Assess the impact of the dystonia on function, pain /comfort (including sleep), and care-giving and whether management is required.			<i>Not specified</i>	DYST: page 1
		Refer the child or young person for a specialist multidisciplinary team assessment of pain, discomfort, distress and sleep if the cause of these is not clear after routine assessment.	Children and young people under 25	Strong	n.a.	NICE_25: Page 306; 21.6. Rec. 89
		If a trial of analgesia is unsuccessful, refer the child or young person to a specialist pain multidisciplinary team , which may be a palliative care service, for a more detailed assessment.	Children and young people under 25	Strong	Expert opinion	NICE_25: Page 313; 22.6. Rec. 99
H2	Analgesia	In the absence of an identifiable cause of pain, discomfort or distress in a child or young person with cerebral palsy: take into account the impact of anxiety, depression or other possible mental health problems; consider a 'stepped approach' trial of simple analgesia (such as paracetamol and/or ibuprofen) for mild to moderate pain ; monitor the duration, pattern and severity of symptoms.	Children and young people under 25	Conditional	Expert opinion	NICE_25: Page 313; 22.6. Rec. 98
H3	Orthoses	Consider orthoses for children and young people with spasticity based on their individual needs and aimed at specific goals, such as: improving posture; improving upper limb function; improving walking efficiency; preventing or slowing development of contractures; preventing or slowing hip migration; relieving discomfort or pain ; preventing or treating tissue injury, for example by relieving pressure points.	Children and young people with spasticity under 19s	Conditional	Low	NICE_19: Page 108; Rec. 37

H4	Education and counseling					
		Explain to children and young people with cerebral palsy and their parents or carers that pain is common in people with cerebral palsy, especially those with more severe motor impairment, and this should be recognised and addressed.	Children and young people under 25	Strong	Very low to moderate	NICE_25: Page 299; 20.6. Rec. 84
		For common interventions used in the management of cerebral palsy (such as physical therapies, botulinum toxin A injections and surgery) that can cause acute pain: advise the child or young person and their parents or carers that these interventions may reduce discomfort in the long term; minimise discomfort during these procedures.	Children and young people under 25	Strong	Expert opinion	NICE_25: Page 313; 22.6. Rec. 97
		If an adult with cerebral palsy has difficulty communicating: discuss with their family or carers how best to identify pain and include this information in their care plan use observational or descriptive pain scales to assess the presence, severity and location of pain.	Adults with difficulty communicating	Strong	Low to moderate	NICE_Ad: Page 28; 4.38

NOTES:

I) Interventions for Bowel and bladder management and toileting

N°	Intervention	Original recommendation	Specification of target population	SoR	QoE	Ref.
DEFECATION FUNCTIONS						
I1	Assessment	At every review, discuss with adults with cerebral palsy (and their family and Cerebral palsy in adults carers, if agreed) whether they have difficulties with eating or if there have been any changes in their eating habits or bowel function . Ask about issues including: changes in appetite; changes in the person's ability to feed themselves; constipation; coughing or choking when eating; food refusal; increased frequency of chest infections (which may be related to swallowing; difficulties or gastro-oesophageal reflux); an increase in the length of meal times.	Adults	Strong	Expert opinion	NICE_Ad: Page 23; 4.17

NOTES:

J) Interventions for Sexual functions and intimate relationships

N°	Intervention	Original recommendation	Specification of target population	SoR	QoE	Ref.
MENSTRUATION FUNCTIONS						
J1	Education and counseling	Ensure that the child or young person and their parents or carers are provided with information , by a professional with appropriate expertise, about the following topics relevant to them that is tailored to their individual needs: menstruation , fertility and contraception, sex and sexuality, parenting.	Children and young people under 25	Strong	Low to moderate	NICE_25: Page 182; 11.6. Rec. 40
FERTILITY						
J2	Education and counseling	Ensure that the child or young person and their parents or carers are provided with information , by a professional with appropriate expertise, about the following topics relevant to them that is tailored to their individual needs: menstruation, fertility and contraception , sex and sexuality, parenting.	Children and young people under 25	Strong	Low to moderate	NICE_25: Page 182; 11.6. Rec. 40
INTIMATE RELATIONSHIPS						
J3	Education and counseling	Ensure that the child or young person and their parents or carers are provided with information , by a professional with appropriate expertise, about the following topics relevant to them that is tailored to their individual needs: sex and sexuality ,	Children and young people under 25	Strong	Low to moderate	NICE_25: Page 182; 11.6. Rec. 40

NOTES:

K) Interventions for Respiration functions

N°	Intervention	Original recommendation	Specification of target population	SoR	QoE	Ref.
RESPIRATION FUNCTIONS						
K1	Assessment	Consider assessment with spirometry for adults with cerebral palsy who are suspected to be at high risk of respiratory impairment.	Adults who are at high risk of respiratory impairment	Conditional	Expert opinion	NICE_Ad: Page 26; 4.25
K2	Home based non-invasive ventilation	Consider home-based non-invasive ventilation for adults with cerebral palsy and respiratory failure.	Adults with respiratory failure	Conditional	Expert opinion	NICE_Ad: Page 27; 4.31
		If a person with cerebral palsy is having home-based non-invasive ventilation, carry out a review with a multidisciplinary team every 3 to 6 months. Assess and discuss with the person (and their family and carers, if agreed) the effectiveness, tolerability and whether agreed goals are being met.	Adults	Strong	Expert opinion	NICE_Ad: Page 27; 4.32
K3	Tracheostomy or supportive care	If the agreed treatment goals are not met by non-invasive ventilation, consider alternative treatment options, such as tracheostomy or supportive care , and discuss them with the person with cerebral palsy, taking into account their preferences for future treatment (see recommendation 1.4.33).	Adults; If the agreed treatment goals are not met by non-invasive ventilation	Conditional	Expert opinion	NICE_Ad: Page 27; 4.34
K4	Education and counseling	If a person with cerebral palsy has symptoms of respiratory failure, or is at high risk of developing respiratory failure, discuss their management plan with them (and their family or carers, if agreed), including: assessing the effectiveness and tolerability of treatment; treatment goals and escalation plan of treatment; managing complications; options for managing progressive respiratory failure.	Adults	Strong	Expert opinion	NICE_Ad: Page 27; 4.30
		If a person with cerebral palsy is having non-invasive ventilation, discuss with them (and their family or carers, if agreed) their preferences for future treatment . Agree a plan for what should happen if an intercurrent infection (occurring during the progress of respiratory failure) causes an acute deterioration in respiratory function and record this in the person's advance care plan.	Adults having non-invasive ventilation	Strong	Expert opinion	NICE_Ad: Page 27; 4.33
PREVENTION OF RESPIRATORY CONDITIONS						
K5	Vaccination	Offer vaccinations to adults with cerebral palsy and their carers, in line with the national immunisation programme (see the Green Book for further information).	Adults	Strong	Expert opinion	NICE_Ad: Page 26; 4.26
K6	Pharmacological agents	Do not offer prophylactic antibiotics for lower respiratory tract infections in adults with cerebral palsy, unless: the person is at high risk of respiratory impairment (see recommendation 1.4.23) and they are offered on the advice of a respiratory specialist with expertise in neurodisability management.	Adults	Strong against	Expert opinion	NICE_Ad: Page 26; 4.27

K7	Postural management	If an adult with cerebral palsy is at high risk of lower respiratory tract infection, consider a prophylactic physiotherapy chest care review . This may include: postural management ; advice on exercise; advice on training and care for family members and carers.	Adults at high risk of lower respiratory tract infection	Conditional	Expert opinion	NICE_Ad: Page 26; 4.28
K8	Education and counseling	If an adult with cerebral palsy is at high risk of lower respiratory tract infection, consider a prophylactic physiotherapy chest care review . This may include: postural management; advice on exercise ; advice on training and care for family members and carers .	Adults at high risk of lower respiratory tract infection	Conditional	Expert opinion	NICE_Ad: Page 26; 4.28

NOTES:

L) Interventions for Skin care

N°	Intervention	Original recommendation	Specification of target population	SoR	QoE	Ref.
PREVENTION/TREATMENT OF TISSUE INJURIES						
L1	Orthoses	Consider orthoses for children and young people with spasticity based on their Individual needs and aimed at specific goals, such as: improving posture; improving upper limb function; improving walking efficiency; preventing or slowing development of contractures; preventing or slowing hip migration; relieving discomfort or pain; preventing or treating tissue injury , for example by relieving pressure points.	Children and young people with spasticity under 19s	Conditional	Low	NICE_19: Page 108; Rec. 37

NOTES:

N) Rehabilitation interventions for motor functions and mobility

N°	Intervention	Original recommendation	Specification of target population	SoR	QoE	Ref.
NEUROMUSCULOSKELETAL AND MOVEMENT RELATED FUNCTIONS						
N1	Education and counseling	Discuss with adults with cerebral palsy (and their families or carers, if agreed) that: their musculoskeletal function may deteriorate gradually, and any changes should be investigated to identify treatable causes early recognition of bone and joint disorders enables early treatment, which may improve outcomes.	Adults	Strong	Very low	NICE_Ad: Page 20; 4.1
MOBILITY OF JOINT FUNCTIONS						
N2	Assessment	When considering botulinum toxin type A treatment, perform a careful assessment of muscle tone, range of movement and motor function to: inform the decision as to whether the treatment is appropriate; provide a baseline against which the response to treatment can be measured. A physiotherapist or an occupational therapist should be involved in the assessment.	Children and young people with spasticity under 19s	Strong	Low to Moderate	NICE_19:P age 168; Rec. 71
		Perform an assessment of muscle tone, range of movement and motor function: 6–12 weeks after injections to assess the response; 12–26 weeks after injections to inform decisions about further injections. These assessments should preferably be performed by the same health care professionals who undertook the baseline assessment.	Children and young people with spasticity under 19s	Strong	Low to Moderate	NICE_19:P age 168; Rec. 81
N3	24-Hour Postural Management	Consider including in the physical therapy programme 24-hour postural management strategies to: prevent or delay the development of contractures or skeletal deformities in children and young people at risk of developing these; enable the child or young person to take part in activities appropriate to their stage of development.	Children and young people under 19s at risk of developing contractures	Conditional	Expert opinion	NICE_19: Page 76; Rec. 27
		When using 24-hour postural management strategies consider on an individual basis low-load active stretching or low-load passive stretching.	Children and young people with spasticity under 19s	Conditional	Expert opinion	NICE_19: Page 76; Rec. 28
N4	Orthoses	Consider orthoses for children and young people with spasticity based on their individual needs and aimed at specific goals, such as: improving posture; improving upper limb function; improving walking efficiency; preventing or slowing development of contractures ; preventing or slowing hip migration; relieving discomfort or pain; preventing or treating tissue injury, for example by relieving pressure points.	Children and young people with spasticity under 19s	Conditional	Low	NICE_19:P age 108; Rec.37
		Consider the following orthoses for children and young people with upper limb spasticity: elbow gaiters to maintain extension and improve function ; rigid wrist orthoses to prevent contractures and limit wrist and hand flexion deformity; dynamic orthoses to improve hand function (for example, a non-rigid thumb abduction splint allowing some movement for a child or young person with a 'thumb in palm' deformity).	Children and young people with spasticity under 19s	Conditional	Low	NICE_19: Page 109; Rec. 45
		Serial casting should follow BoNT-A for management of fixed calf contracture.	Children (<18) with cerebral palsy having spasticity in the lower limbs	U	Class IV (Expert opinion)	LOVE: Page 21; Rec. 5;
		AFOs are an effective adjunctive intervention to improve gait and protect foot integrity.	Children (<18) with	U	Class IV	LOVE:

			cerebral palsy having spasticity in the lower limbs		(Expert opinion)	Page 21; Rec. 5;
		Consider the following orthoses for children and young people with upper limb spasticity: elbow gaiters to maintain extension and improve function; rigid wrist orthoses to prevent contractures and limit wrist and hand flexion deformity; dynamic orthoses to improve hand function (for example, a non-rigid thumb abduction splint allowing some movement for a child or young person with a 'thumb in palm' deformity).	Children and young people with spasticity under 19s	Conditional	Low	NICE_19: Page 109; Rec. 45
		Be aware that in children and young people with secondary complications of spasticity, for example contractures and abnormal torsion, ankle-foot orthoses may not be beneficial .	In children and young people under 19s with secondary complications of spasticity (contractures and abnormal torsion)	Strong	Low	NICE_19: Page 109; Rec. 47
		Consider the overnight use of orthoses to: improve posture; prevent or delay hip migration; prevent or delay contractures .	Children and young people with spasticity under 19s	Conditional	Low	NICE_19: Page 109; Rec. 51
N5	Education and counseling	Offer training to parents and carers involved in delivering postural management strategies.	Children and young people with spasticity under 19s	Strong	Expert opinion	NICE_19: Page 76; Rec. 29
STABILITY OF JOINT FUNCTIONS						
N6	Assessment (X-Ray)	Offer a hip X-ray to assess for hip displacement; if there are clinical concerns about possible hip displacement at 24 months in children with bilateral cerebral palsy.	Children and young people with spasticity under 19s	Strong	Expert opinion	NICE_19: Page 75; Rec. 17
		Consider repeating the hip X-ray annually in children or young people who are at Gross Motor Function Classification System (GMFCS) level III, IV or V.	Children and young people with spasticity under 19s: who are at Gross Motor Function Classification System (GMFCS) level III, IV or V.	Conditional	Expert opinion	NICE_19: Page 75; Rec. 18
		Consider repeating the hip X-ray after 6 months in children and young people where the initial hip migration is greater than 30%, and then consider repeating the hip X-ray every 6 months after this if the hip migration is increasing by more than 10 percentage points per year.	Children and young people with spasticity under 19s (initial hip migration is greater than 30%)	Conditional	Expert opinion	NICE_19: Page 75; Rec. 19
		Do not offer an X-ray to assess for hip subluxation or curvature of the spine in adults with cerebral palsy, unless the person is in pain or their posture or function is affected.	Adults; if pain or their posture or function is affected.	Strong against	Very low	NICE_Ad: Page 21; 4.8
		Do not offer an X-ray to assess for hip subluxation or curvature of the spine in adults with	Adults; if pain or their	Strong	Very low	NICE_Ad:

		cerebral palsy, unless the person is in pain or their posture or function is affected.	posture or function is affected.	against		Page 21; 4.8
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N7	Botulinum toxin injections	BoNT-A injections to the adductor (and hamstring) muscles may delay hip displacement, but does not affect long-term outcome (level A)	Children (<18) having spasticity in the lower limbs	A against	Class I: 1	LOVE: Page 17; Rec. 3
N8	Orthoses and splints	Consider orthoses for children and young people with spasticity based on their individual needs and aimed at specific goals, such as: improving posture; improving upper limb function; improving walking efficiency; preventing or slowing development of contractures; preventing or slowing hip migration ; relieving discomfort or pain; preventing or treating tissue injury, for example by relieving pressure points.	Children and young people with spasticity under 19s	Conditional	Low	NICE_19: Page 108; Rec. 37
		Consider the overnight use of orthoses to: improve posture; prevent or delay hip migration ; prevent or delay contractures.	Children and young people with spasticity under 19s	Conditional	Low	NICE_19: Page 109; Rec. 51
		Rehabilitation strategies used by physiotherapists, occupational therapists and speech pathologists are generally considered cornerstones in the management of dystonia in CP. General principles include: 1) ensuring therapy is goal-directed, 2) avoiding asymmetry and aiming for symmetrical positioning to enhance motor control, 3) optimizing seating and positioning with good stability/support, 4) considering orthoses and splints to increase stability and coordination, and 5) considering the need for communication supports.	Individuals at all ages with dystonia in CP	Level U	Expert opinion	DYST: page 1
MUSCLE POWER FUNCTIONS						
N9	Muscle strengthening	Strengthening is an essential adjunctive intervention to BoNT-A when goals to improve motor function are identified.	Children (<18) with cerebral palsy having spasticity in the lower limbs	U	Class IV (Expert opinion)	Page 21; Rec. 5;
		Consider muscle-strengthening therapy where the assessment indicates that muscle weakness is contributing to loss of function or postural difficulties.	Children and young people with spasticity under 19s	Conditional	Low	NICE_19: Page 76; Rec. 32
		Direct muscle-strengthening therapy towards specific goals using progressive repetitive exercises performed against resistance.	Children and young people with spasticity under 19s	Strong	Low	NICE_19: Page 77; Rec. 33
MUSCLE TONE FUNCTIONS (SPASTICITY)						
N10	Assessment	Carefully assess the impact of spasticity in children and young people with cognitive impairments: be aware that the possible benefit of treatments may be more difficult to assess in a child or young person with limited communication ensure that the child or young person has access to all appropriate services.	Children and young people under 19s	Strong	Expert opinion	NICE_19: Page 74; Rec. 7
		When considering botulinum toxin type A treatment, perform a careful assessment of muscle tone , range of movement and motor function to: inform the decision as to whether the treatment is appropriate; provide a baseline against which the response to treatment can be measured. A physiotherapist or an occupational therapist should be	Children and young people with spasticity under 19s	Strong	Low to Moderate	NICE_19: Page 168; Rec. 71

		involved in the assessment.				
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		Perform an assessment of muscle tone , range of movement and motor function: 6–12 weeks after injections to assess the response; 12–26 weeks after injections to inform decisions about further injections. These assessments should preferably be performed by the same healthcare professionals who undertook the baseline assessment.	Children and young people with spasticity under 19s	Strong	Low to Moderate	NICE_19: Page 168; Rec. 81
		Reliably differentiate the spasticity from fixed musculoskeletal contractures and other causes of hypertonia*	Children (<18) with cerebral palsy having spasticity in the lower limbs	U	Class IV (Expert opinion)	LOVE: Page 11; Rec.1;
		Muscle length (R2), Modified Tardieu Score (R1) and Australian Spasticity Assessment Scale (ASAS) when presented together profile and quantify spasticity*	Children (<18) with cerebral palsy having spasticity in the lower limbs	U	Class IV (Expert opinion)	LOVE: Page 14; Rec. 2;
		At every review, discuss with the person with cerebral palsy (and their family and carers, if agreed) factors that may exacerbate their spasticity or dystonia , such as: bladder problems (for example, urinary tract infection or bladder stones); constipation; emotional distress; pain; posture; pressure sores; changes in home or work environments, including seating; medication changes and side effects.	Adults	Strong	Very low to low	NICE_Ad: Page 14; 3.4
		Before discussing further management options for spasticity or dystonia with a person with cerebral palsy: address any modifiable factors identified that may be exacerbating the spasticity or dystonia and review their physical management programme.	Adults	Strong	Very low to low	NICE_Ad: Page 15; 3.5
N11	Oral Diazepam	Consider oral diazepam in children and young people if spasticity is contributing to one or more of the following: discomfort or pain muscle spasms (for example, night-time muscle spasms) functional disability. Diazepam is particularly useful if a rapid effect is desirable (for example, in a pain crisis).	Children and young people with spasticity under 19s	Conditional	Moderate	NICE_19: Page 128; 55
		Give oral diazepam treatment as a bedtime dose. If the response is unsatisfactory consider: increasing the dose or adding a daytime dose.	Children and young people with spasticity under 19s	Conditional	Moderate	NICE_19: Page 128; 58
		Do not offer diazepam for spasticity in adults with cerebral palsy, except in an acute situation when spasticity is causing severe pain or anxiety.	Adults	Strong against	Very low to low	NICE_Ad: Page 16; 3.9
N12	Oral Baclofen	Consider oral baclofen if spasticity is contributing to one or more of the following: discomfort or pain; muscle spasms (for example, night-time muscle spasms); functional disability. Baclofen is particularly useful if a sustained long-term effect is desired (for example, to relieve continuous discomfort or to improve motor function).	Children and young people with spasticity under 19s	Conditional	Low to Moderate	NICE_19: Page 128; 56
		If oral diazepam is initially used because of its rapid onset of action, consider changing to oral baclofen if long-term treatment is indicated.	Children and young people with spasticity under 19s	Conditional	Moderate	NICE_19: Page 128; 57
		Start oral baclofen treatment with a low dose and increase the dose stepwise over about 4 weeks to achieve the optimum therapeutic effect.	Children and young people with spasticity under 19s	Strong	Low to Moderate	NICE_19: Page 128; 59

N13	Oral Baclofen and Diazepam	If adverse effects (such as drowsiness) occur with oral diazepam or oral baclofen , think about reducing the dose or stopping treatment.	Children and young people with spasticity under 19s	Strong	Low to Moderate	NICE_19: Page 128; 61
		If the response to oral diazepam and oral baclofen used individually for 4–6 weeks is unsatisfactory, consider a trial of combined treatment using both drugs.	Children and young people with spasticity under 19s;	Conditional	Low to Moderate	NICE_19: Page 128; 62
		If a child or young person has been receiving oral diazepam and/or baclofen for several weeks, ensure that when stopping these drugs the dose is reduced in stages to avoid withdrawal symptoms.	Children and young people with spasticity under 19s	Strong	Low to Moderate	NICE_19: Page 128; 63
N14	Botulinum Toxin Type A	Consider botulinum toxin type A [5] treatment in children and young people in whom focal spasticity of the upper limb is impeding fine motor function compromising care and hygiene, causing pain, impeding tolerance of other treatments, such as orthoses, causing cosmetic concerns to the child or young person.	Children and young people with spasticity under 19s	Conditional	Low to Moderate	NICE_19: Page 167; Rec. 65
		Consider botulinum toxin type A [5] treatment where focal spasticity of the lower limb is: impeding gross motor function; compromising care and hygiene; causing pain disturbing sleep, impeding tolerance of other treatments, such as orthoses and use of equipment to support posture, causing cosmetic concerns to the child or young person.	Children and young people with spasticity under 19s	Conditional	Low to Moderate	NICE_19: Page 167; Rec. 66
		Consider botulinum toxin type A [5] treatment after an acquired non-progressive brain injury if rapid-onset spasticity is causing postural or functional difficulties.	Children and young people with spasticity under 19s	Conditional	Low to Moderate	NICE_19: Page 167; Rec. 67
		Consider repeat injections of botulinum toxin type A if the response in relation to the child or young person's treatment goal was satisfactory, and the treatment effect has worn off new goals amenable to this treatment are identified.	Children and young people with spasticity under 19s	Conditional	Low to Moderate	NICE_19: Page 168; Rec. 82
		Consider ultrasound or electrical muscle stimulation to guide the injection of botulinum toxin type A	Children and young people with spasticity under 19s	Conditional	Low to Moderate	NICE_19: Page 168; Rec. 76
		Consider injecting botulinum toxin type A into more than one muscle if this is appropriate to the treatment goal, but ensure that maximum dosages are not exceeded.	Children and young people with spasticity under 19s	Conditional	Low to Moderate	NICE_19: Page 168; Rec. 77
		Do not offer botulinum toxin type A treatment if the child or young person: has severe muscle weakness, had a previous adverse reaction or allergy to botulinum toxin type A, is receiving aminoglycoside treatment.	Children and young people with spasticity under 19s	Strong against	Low to Moderate	NICE_19: Page 168; Rec. 69
		Be cautious when considering botulinum toxin type A treatment if the child or young person has any of the following: a bleeding disorder, for example due to anti-coagulant therapy; generalized spasticity; fixed muscle contractures; marked bony deformity; or	Children and young people with spasticity under 19s	Strong	Low to Moderate	NICE_19: Page 168; Rec.

		there are concerns about the child or young person's likelihood of engaging with the post-treatment adapted physical therapy programme (see recommendation 1.2.15).				70
		BoNT-A is established as effective in the management of spastic equinus to improve gait.	Children (<18) with cerebral palsy having spasticity in the lower limbs	A	Class I	LOVE: Page 17; Rec. 3;
		BoNT-A is probably effective to improve goal attainment and function in the management of spastic equinus.	Children (<18) with cerebral palsy having spasticity in the lower limbs	B	Class II	LOVE: Page 17; Rec. 3;
		BoNT-A is similar to serial casting in the management of spastic equinus with current data being inadequate or conflicting	Children (<18) with cerebral palsy having spasticity in the lower limbs	U = no recommendation	Class II	LOVE: Page 17; Rec. 3;
		BoNT-A injections to the adductor muscles is probably effective in some specific areas of goal attainment	Children (<18) with cerebral palsy having spasticity in the lower limbs	B	Class I: 2; Class II: 1; Class III: 1	LOVE: Page 17; Rec. 3;
		Consider referring adults with cerebral palsy for botulinum toxin type A[2] treatment if: they have spasticity in a limited number of muscle groups that is: affecting their care (such as hygiene or dressing) or causing pain or impairing activity and participation, or a tone management specialist agrees that treatment targeted to focal muscle groups is likely to improve their function and symptoms.	Adults	Conditional	Very low to low	NICE_Ad: Page 16; 3.11

Cochrane Systematic Review: Hoare B et al. 2010; Botulinumtoxin A as an adjunct to treatment in the management of the upper limb in children with spastic cerebral palsy.

N of included studies (total participants): 10 (397)

Population: Children with cerebral palsy

Setting: Outpatients, community

Intervention	Control	Outcome	No of studies	No of participants	Corresponding risk (95% CI)	Quality of evidence (GRADE)	Statistical method	Heterogeneity
BoNT-A	Placebo/ no treatment	Elbow flexor spasticity	1	34	-9.55 [-25.93, 6.83]	Moderate	Mean Difference (IV, Random, 95% CI)	NA
		Wrist flexor spasticity	1	34	-9.01 [-32.74, 14.72]	Moderate		NA
		Quality of movement (18 mths - 8yrs)	1	13	8.60 [-8.47, 25.67]	Moderate		NA
		Quality of movement (5yrs - 15yrs)	1	21	-2.80 [-8.29, 2.69]	Moderate		NA
		Goal attainment	1	32	9.24 [0.92, 17.56]	Moderate		NA
		Occupational performance - performance	1	34	1.10 [0.19, 2.01]	High		NA
		Occupational performance - satisfaction	1	34	1.40 [0.22, 2.58]	High		NA
BoNT-A		Elbow flexor spasticity	1	36	-27.43 [-43.09, -11.77]	High		NA

	Occupational Therapy (OT)	Wrist flexor spasticity	1	36	-21.81 [-33.65, -9.97]	High	NA
		Quality of movement (18 mths - 8yrs)	3	84	9.19 [4.48, 13.54]	High	I2 =0.0% (P = 0.74);
		Quality of movement (5yrs - 15yrs)	3	69	4.46 [-0.77, 9.69]	High	I2 =50% (P = 0.13);
		Goal attainment	4	152	8.52 [4.42, 12.62]	High	I2 =27% (P = 0.25);
		Occupational performance - performance	3	109	0.77 [0.23, 1.31]	High	I2 =0.0% (P = 0.82);
		Occupational performance - satisfaction	3	109	0.81 [0.17, 1.46]	High	I2 =0.0% (P = 0.78);
BoNT-A/OT	BoNT-A only	Elbow flexor spasticity	1	39	1.08 [-21.59, 19.43]	Moderate	NA
		Wrist flexor spasticity	1	39	-19.07 [-35.02, -3.12]	High	NA
		Quality of movement (18 mths - 8yrs)	1	14	7.40 [-8.45, 23.25]	Moderate	NA
		Quality of movement (5yrs - 15yrs)	1	22	5.30 [0.95, 9.65]	High	NA
		Goal attainment	1	39	8.69 [0.48, 16.90]	High	NA
		Occupational performance - performance	1	39	0.60 [-0.44, 1.64]	Moderate	NA
		Occupational performance - satisfaction	1	39	0.70 [-0.71, 2.11]	Moderate	NA
							NA
BoNT-A/OT	Placebo/no treatment	Elbow flexor spasticity	1	35	-10.63 [-26.40, 5.14]	Moderate	NA
		Wrist flexor spasticity	1	35	-28.08 [-48.71, -7.45]	High	NA
		Quality of movement (18 mths - 8yrs)	1	13	16.00 [0.50, 31.5]	Moderate	NA
		Quality of movement (5yrs - 15yrs)	1	19	2.50 [-2.60, 7.60]	Moderate	NA
		Goal attainment	1	33	17.93 [10.17, 25.69]	High	NA
		Occupational performance - performance	1	35	1.7 [0.7, 2.7]	High	NA
		Occupational performance - satisfaction	1	35	2.1 [0.83, 3.37]	High	NA
							NA
BoNT-A only	OT only	Elbow flexor spasticity	1	35	-26.36 [-42.63, -10.09]	High	NA
		Wrist flexor spasticity	1	35	-2.74 [-19.41, 13.93]	Moderate	NA
		Quality of movement (18 mths - 8yrs)	1	13	-1.4 [-20.95, 18.15]	Moderate	NA
		Quality of movement (5yrs - 15yrs)	1	21	-3.7 [-10.15, 2.75]	Moderate	NA
		Goal attainment	1	36	-0.07 [-8.05, 7.91]	Moderate	NA
		Occupational performance - performance	1	36	0.2 [-0.85, 1.25]	Moderate	NA
		Occupational performance - satisfaction	1	36	0.3 [-1.01, 1.61]	Moderate	NA
							NA
High dose BoNT-A	Low dose BoNT-A	Quality of movement (18 mths - 8yrs)	1	39	1.75 [-6.67, 10.17]	Moderate	NA

N15	Enteral Baclofen	Consider enteral baclofen[1] as the first-line drug treatment for adults with cerebral palsy and generalised spasticity causing: functional impairment or pain or spasms.	Adults	Conditional	Very low to low	NICE_Ad: Page 15; 3.6
		Start enteral baclofen[1] treatment with a low dose and increase the dose gradually over about 4 weeks to achieve the optimum therapeutic effect.	Adults	Strong	Very low to low	NICE_Ad: Page 15; 3.7
N16	Continuous pump-administered intrathecal baclofen	Consider treatment with continuous pump-administered intrathecal baclofen[7] in children and young people with spasticity if, despite the use of non-invasive treatments, spasticity or dystonia are causing difficulties with any of the following: pain or muscle	Children and young people with spasticity under 19s	Conditional	Very low to Moderate	NICE_19: Page 204; Rec.

		spasms, posture or function, self-care (or ease of care by parents or carers).				83
		Consider referring adults with cerebral palsy to a tone or spasticity management service offering continuous pump-administered intrathecal baclofen therapy if they still have difficulties with spasticity, despite enteral muscle relaxant drug treatment or botulinum toxin type A treatment.	Adults	Conditional	Very low to low	NICE_Ad: Page 16; 3.12

		Implant the infusion pump and start treatment with continuous pump-administered intrathecal baclofen within 3 months of a satisfactory response to intrathecal baclofen testing (see recommendation 1.6.13).	Children and young people with spasticity under 19s	Strong	Very low to Moderate	NICE_19: Page 206; Rec. 100
		Titrate the dose of intrathecal baclofen after pump implantation, if necessary, to optimise effectiveness.	Children and young people with spasticity under 19s	Strong	Very low to Moderate	NICE_19: Page 206; Rec.104
N17	Selective dorsal rhizotomy	Only consider selective dorsal rhizotomy for adults with cerebral palsy and spasticity if other treatments have been unsuccessful or are contraindicated, and after they have been assessed by a multidisciplinary team with: specialist training and expertise in the care of spasticity and access to the full range of treatment options.	Adults	Conditional	Very low to low	NICE_Ad: Page 17; 3.17
N18	Education and counseling	Verbal and written explanation of both potential benefits and possible adverse events should be given to parents or carers before the first injection. Parents should be taught how to identify the signs and symptoms of an adverse event (such as dysphagia, dysphonia, dyspnoea, respiratory distress, generalized weakness or incontinence) and instructed to seek medical attention immediately if the child experiences difficulty swallowing, talking, breathing, or muscle weakness.	Children (<18) with cerebral palsy having spasticity in the lower limbs	not available	not available	LOVE: Page 22; Rec. 6;
		Discuss with the adult with cerebral palsy (and their family and carers, if agreed) treatments for spasticity or dystonia , including: personal treatment goals (which should be documented) and; the benefits and risks of treatments (for example, the risk of deterioration in function) as part of their multidisciplinary treatment strategy.	Adults	Strong	Very low to low	NICE_Ad: Page 13; 3.1
		Discuss with the person with cerebral palsy (and their family and carers, if agreed) the balance between the benefits and harms of treating spasticity and dystonia . In particular, explain that some people use their spasticity or dystonia to help their posture and ability to stand, walk or transfer, and that treatment may affect this	Adults	Strong	Very low to low	NICE_Ad: Page 13; 3.2
		When considering botulinum toxin type A treatment, give the child or young person and their parents or carers information about: the possible benefits and the likelihood of achieving the treatment goals what the treatment entails, including: the need for assessments before and after the treatment; the need to inject the drug into the affected muscles the possible need for repeat injections; the benefits, where necessary, of analgesia, sedation or general anaesthesia the need to use serial casting or an orthosis after the treatment in some cases; possible important adverse effects (see also recommendation 1.5.10).	Children and young people with spasticity under 19s	Strong	Low to Moderate	NICE_19: Page 168; Rec. 72
		Before starting treatment with botulinum toxin type A , tell children and young people and their parents or carers: to be aware of the following rare but serious complications of botulinum toxin type A treatment: swallowing difficulties; breathing difficulties; how to recognise signs suggesting these complications are present; that these complications may occur at any time during the first week after the treatment and; that if these complications occur the child or young person should return to hospital immediately.	Children and young people with spasticity under 19s	Strong	Low to Moderate	NICE_19: Page 168; Rec. 74
		If botulinum toxin type A[5] is a proposed treatment option, take into account and ex-	Adults	Strong	Very low to	NICE_Ad:

		plain to the adult with cerebral palsy (and their family and carers, if agreed): that the severity and pattern of dystonia may change after treatment and the potential impact of treatment on function.			low	Page 19; 3.23
		When considering continuous pump-administered intrathecal baclofen, balance the benefits of reducing spasticity against the risk of doing so because spasticity sometimes supports function (for example, by compensating for muscle weakness). Discuss these possible adverse effects with the child or young person and their parents or carers.	Children and young people with spasticity under 19s	Strong	Very low to Moderate	NICE_19: Page 204; Rec. 88
		When considering continuous pump-administered intrathecal baclofen , give the person (and their family and carers, if agreed) information and discuss the procedure with them. This should include : the need for an intrathecal baclofen test to ensure treatment is suitable the surgical procedure for implanting the pump the need for regular hospital follow-up visits to ensure optimal dosage and pump refill the risks of implanting a pump and pump-related complications (for example, battery failure or catheter leakage), which can result in baclofen withdrawal or overdose a review of 24-hour postural needs.	Adults	Strong	Very low to low	NICE_Ad: Page 16; 3.13
		Only consider continuous pump-administered intrathecal baclofen[6] if people with cerebral palsy still have difficulties with dystonia, despite having enteral anti-dystonic drug treatment or botulinum toxin type A[5] treatment. Provide information and discuss the procedure, including intrathecal baclofen testing , with the person (and their family or carer, if agreed) as described in recommendations	Adults still have difficulties with dystonia, despite having enteral anti-dystonic drug treatment or botulinum toxin type A[5] treatment.	Conditional	Very low to low	NICE_Ad: Page 19; 3.24
		Before intrathecal baclofen testing, inform children and young people and their parents or carers verbally and in writing (or appropriate formats) about: what the test will entail adverse effects that might occur with testing how the test might help to indicate the response to treatment with continuous pump administered intrathecal baclofen, including whether: the treatment goals are likely to be achieved; adverse effects might occur.	Children and young people with spasticity under 19s	Strong	Very low to Moderate	NICE_19: Page 205; Rec. 91
		Before implanting the intrathecal baclofen pump, inform children and young people and their parents or carers, verbally and in writing (or appropriate formats) , about: safe and effective management of continuous pump-administered intrathecal baclofen; the effects of intrathecal baclofen, possible adverse effects, and symptoms and signs suggesting the dose is too low or too high; the potential for pump-related complications; the danger of stopping the continuous pump-administered intrathecal baclofen infusion suddenly; the need to attend hospital for follow-up appointments, for example to refill and reprogram the infusion pump; the importance of seeking advice from a healthcare professional with expertise in intrathecal baclofen before stopping the treatment.	Children and young people with spasticity under 19s	Strong	Very low to Moderate	NICE_19: Page 206; Rec. 99
		When considering continuous pump-administered intrathecal baclofen, inform children and young people and their parents or carers verbally and in writing (or appropriate formats) about: the surgical procedure used to implant the pump, the need for regular hospital follow-up visits, the requirements for pump maintenance, the risks associated with pump implantation, pump-related complications and adverse effects that might	Children and young people with spasticity under 19s	Strong	Very low to Moderate	NICE_19: Page 204; Rec. 89

		be associated with intrathecal baclofen infusion.				
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		Discuss the impact of selective dorsal rhizotomy with the person (and their family and carers, if agreed) when it is a proposed treatment option and provide information. This should include: that the procedure cannot be reversed; the possible complications; the need for prolonged physiotherapy and aftercare the possible impact on function; that the long-term benefits are uncertain.	Adults	Strong	Very low to low	NICE_Ad: Page 18; 3.18
MUSCLE TONE FUNCTIONS (DYSTONIA)						
N19	Assessment	It is recommended that a 'dystonia' assessment be routinely included in your neurological examination (assessing for fluctuating hypertonia, and using tactile stimulation or voluntary movement to trigger dystonia).	Individuals at all ages with dystonia in CP		Not specified	DYST: page 1
		On your examination, determine if the dystonia is generalized or focal and assess the severity (can use a standardized scale such as the Barry Albright Dystonia Scale	Individuals at all ages with dystonia in CP		Not specified	DYST: page 1
		Assess the impact of the dystonia on function , pain/comfort (including sleep), and caregiving and whether management is required.	Individuals at all ages with dystonia in CP		Not specified	DYST: page 1
		At every review, discuss with the person with cerebral palsy (and their family and carers, if agreed) factors that may exacerbate their spasticity or dystonia , such as: bladder problems (for example, urinary tract infection or bladder stones); constipation; emotional distress; pain; posture; pressure sores; changes in home or work environments, including seating; medication changes and side effects.	Adults	Strong	Very low to low	NICE_Ad: Page 14; 3.4
		Before discussing further management options for spasticity or dystonia with a person with cerebral palsy: address any modifiable factors identified that may be exacerbating the spasticity or dystonia and review their physical management programme.	Adults	Strong	Very low to low	NICE_Ad: Page 15; 3.5
		Before performing the intrathecal baclofen test, assess the following where relevant to the treatment goals: spasticity; dystonia ; the presence of pain or muscle spasms; postural difficulties, including head control; functional difficulties; difficulties with self-care (or ease of care by parents or carers). If necessary, assess passive range of movement under general anaesthesia.	Children and young people with spasticity under 19s	Strong	Very low to Moderate	NICE_19: Page 205; Rec.92
N20	Oral Baclofen	Generalized Dystonia Management: With increasing severity of dystonia, additional interventions may be required beginning with oral medications. Oral baclofen is considered a first line medication for the management of dystonia in CP. Common indications include pain or difficulty sleeping associated with dystonia in CP. If the individual does not respond well to oral baclofen, trihexyphenidyl can be used as a second line medication. Other oral medications should be considered for specific indications. For example, the intermittent use of benzodiazepines is helpful for dystonic storms or disturbed sleep, and gabapentin for dystonia associated with pain. Clonidine can also be considered for disturbed sleep associated with dystonia. The majority of the 'expert' group did not find levodopa helpful in reducing dystonia in CP.	Individuals at all ages with dystonia in CP	Level U	Expert opinion	DYST: page 1
		In children and young people with spasticity in whom dystonia is considered to contribute significantly to problems with posture, function and pain, consider a trial of oral drug treatment, for example with trihexyphenidyl [2], levodopa [3]	Children and young people under 19s with spasticity	Conditional	Very low to Moderate	NICE_19: Page 129; 64

		or baclofen.	(dystonia contributes significantly to problems with posture, function and pain)			
N21	Trihexyphenidyl	Generalized Dystonia Management: With increasing severity of dystonia, additional interventions may be required beginning with oral medications. Oral baclofen is considered a first line medication for the management of dystonia in CP. Common indications include pain or difficulty sleeping associated with dystonia in CP. If the individual does not respond well to oral baclofen, trihexyphenidyl can be used as a second line medication. Other oral medications should be considered for specific indications. For example, the intermittent use of benzodiazepines is helpful for dystonic storms or disturbed sleep, and gabapentin for dystonia associated with pain. Clonidine can also be considered for disturbed sleep associated with dystonia. The majority of the 'expert' group did not find levodopa helpful in reducing dystonia in CP.	Individuals at all ages with dystonia in CP	Level U	Expert opinion	DYST: page 1
		In children and young people with spasticity in whom dystonia is considered to contribute significantly to problems with posture, function and pain, consider a trial of oral drug treatment, for example with trihexyphenidyl [2], levodopa [3] or baclofen.	Children and young people under 19s with spasticity	Conditional	Very low to Moderate	NICE_19: Page 129; 64

Cochrane Systematic Review: Harvey A et al. 2018; Trihexyphenidyl for dystonia in cerebral palsy.

N of included studies (total participants): 1 (16)

Population: Children with dystonic cerebral palsy

Setting: Inpatients

Note: Studies were grouped according to the different outcome measures that have been used.

Intervention	Control	Outcome	No of studies	No of participants	Corresponding risk (95% CI)	Relative effect (95% CI)	Quality of evidence (GRADE)	Statistical method	Heterogeneity
Trihexyphenidyl	Placebo	Change in dystonia from baseline	1	16	2.67 [-2.55 to 7.90]		Low	Mean difference [95% CI]	NA
		Adverse effects (mood disturbance, irritability, behavioural change, constipation)	1	16	1000 per 1000	RR 2.54 (1.38 to 4.67)	Low	Risk Ratio (M-H, Fixed, 95% CI)	NA
		Participation in activities of daily living: individual goal setting	1	16	18.86 [5.68 to 32.03]		Low	Mean difference [95% CI]	NA
			1	16	2.91 [1.01 to 4.82]		Low		NA
			1	16	2.24 [0.64 to 3.84]		Low		NA

N22	Levodopa	Do not prescribe levodopa [3] to manage dystonia in adults with cerebral palsy, except in the rare situation when it is used as a therapeutic trial to identify dopa-responsive dystonia.	Adults	Strong	Very low to low	NICE_Ad: Page 18; 3.20
		In children and young people with spasticity in whom dystonia is considered to contribute significantly to problems with posture, function and pain, consider a trial of oral drug treatment, for example with trihexyphenidyl [2], levodopa [3] or baclofen.	Children and young people under 19s with spasticity in whom dystonia is considered to contribute significantly to problems with posture, function and pain	Conditional	Very low to Moderate	NICE_19: Page 129; 64
N23	Benzodiazepines	Generalized Dystonia Management: With increasing severity of dystonia, additional interventions may be required beginning with oral medications. Oral baclofen is considered a first line medication for the management of dystonia in CP. Common indications include pain or difficulty sleeping associated with dystonia in CP. If the individual does not respond well to oral baclofen, trihexyphenidyl can be used as a second line medication. Other oral medications should be considered for specific indications. For example, the intermittent use of benzodiazepines is helpful for dystonic storms or disturbed sleep, and gabapentin for dystonia associated with pain. Clonidine can also be considered for disturbed sleep associated with dystonia. The majority of the 'expert' group did not find levodopa helpful in reducing dystonia in CP.	Individuals at all ages with dystonia with dystonic storms or disturbed sleep	Level U	Expert opinion	DYST: page1
N24	Gabapentin	Generalized Dystonia Management: With increasing severity of dystonia, additional interventions may be required beginning with oral medications. Oral baclofen is considered a first line medication for the management of dystonia in CP. Common indications include pain or difficulty sleeping associated with dystonia in CP. If the individual does not respond well to oral baclofen, trihexyphenidyl can be used as a second line medication. Other oral medications should be considered for specific indications. For example, the intermittent use of benzodiazepines is helpful for dystonic storms or disturbed sleep, and gabapentin for dystonia associated with pain. Clonidine can also be considered for disturbed sleep associated with dystonia. The majority of the 'expert' group did not find levodopa helpful in reducing dystonia in CP.	Individuals at all ages with dystonia associated with pain	Level U	Expert opinion	DYST: page1
N25	Clonidine	Generalized Dystonia Management: With increasing severity of dystonia, additional interventions may be required beginning with oral medications. Oral baclofen is considered a first line medication for the management of dystonia in CP. Common indications include pain or difficulty sleeping associated with dystonia in CP. If the individual does not respond well to oral baclofen, trihexyphenidyl can be used as a second line medication. Other oral medications should be considered for specific indications. For example, the intermittent use of benzodiazepines is helpful for dystonic storms or disturbed sleep, and gabapentin for dystonia associated with pain. Clonidine can also be	Individuals at all ages with dystonic storms or disturbed sleep	Level U	Expert opinion	DYST: page1

		considered for disturbed sleep associated with dystonia. The majority of the 'expert' group did not find levodopa helpful in reducing dystonia in CP.				
N26	Botulinum toxin type A	Consider a trial of botulinum toxin type A [6] treatment in children and young people with spasticity in whom focal dystonia is causing serious problems, such as postural or functional difficulties or pain.	Children and young people under 19s with spasticity (dystonia is causing postural problems or functional difficulties or pain.	Conditional	Low to Moderate	NICE_19: Page 167; Rec. 68
		Only consider botulinum toxin type A [5] treatment for focal dystonia in adults with cerebral palsy when: the person is under the supervision of a tone or spasticity management service, and it is part of a wider programme of therapy and focal dystonia is: affecting their care (such as hygiene or dressing) or causing pain or impairing activity and participation.	Adults	Conditional	Very low to low	NICE_Ad: Page 18; 3.22
		Focal Dystonia Management: For individuals with focal or segmental dystonia associated with persisting postures causing pain or impacting on function/care-giving, periodic injections of Botulinum toxin can be undertaken. Consider targeting both the agonist/antagonist muscles around the joint(s) involved with the dystonic posture.	Individuals with focal or segmental dystonia associated with persisting postures causing pain or impacting on function/care-giving,	Level U	Expert opinion	DYST: page 1
N27	Continuous pump-administered intrathecal baclofen	Consider treatment with continuous pump-administered intrathecal baclofen [7] in children and young people with spasticity if, despite the use of non-invasive treatments, spasticity or dystonia are causing difficulties with any of the following: pain or muscle spasms, posture or function, self-care (or ease of care by parents or carers).	Children and young people with spasticity under 19s	Conditional	Very low to Moderate	NICE_19: Page 204; Rec. 83
		Only consider continuous pump-administered intrathecal baclofen [6] if people with cerebral palsy still have difficulties with dystonia, despite having enteral anti-dystonic drug treatment or botulinum toxin type A[5] treatment. Provide information and discuss the procedure, including intrathecal baclofen testing, with the person (and their family or carer, if agreed) as described in recommendations	Adults still have difficulties with dystonia, despite having enteral anti-dystonic drug treatment or botulinum toxin type A[5] treatment.	Conditional	Very low to low	NICE_Ad: Page 19; 3.24
		In the presence of severe generalized dystonia associated with significant impact on care/comfort, more aggressive management can be undertaken. This may include intra-thecal baclofen (ITB) or deep brain stimulation (DBS). These strategies require a referral to a specialist team. Individuals with severe generalized hypertonia with a combination of dystonia and spasticity may trial intrathecal baclofen. Other considerations of whether to choose ITB or DBS can be based on the cerebral anatomy and whether placement of the stimulator in the globus pallidus is possible. ITB should be used with caution in the presence of nocturnal respiratory compromise. In the presence of dystonia with pain, other 'generic' pain management strategies can be undertaken.	Individuals at all ages with dystonia in CP	Level C	Level C; probably or possibly effective	DYST: page 1

N28	Deep brain stimulation	If adults with cerebral palsy continue to have severe and painful dystonia, despite having enteral anti-dystonic drug treatment or botulinum toxin type A treatment, consider referring them to a specialised centre with experience in providing deep brain stimulation .	Adults with severe and painful dystonia, despite having enteral anti-dystonic drug treatment or botulinum toxin type A treatment	Conditional	Very low to low	NICE_Ad: Page 19; 3.25
		In the presence of severe generalized dystonia associated with significant impact on care/comfort, more aggressive management can be undertaken. This may include intrathecal baclofen (ITB) or deep brain stimulation (DBS) . These strategies require a referral to a specialist team. Individuals with severe generalized hypertonia with a combination of dystonia and spasticity may trial intrathecal baclofen. Other considerations of whether to choose ITB or DBS can be based on the cerebral anatomy and whether placement of the stimulator in the globus pallidus is possible.	Individuals at all ages with dystonia in CP	Level C; <i>probably or possibly effective</i>		DYST: page 1
N29	Education and counseling on treatment	Discuss with the adult with cerebral palsy (and their family and carers, if agreed) treatments for spasticity or dystonia , including: personal treatment goals (which should be documented) and; the benefits and risks of treatments (for example, the risk of deterioration in function) as part of their multidisciplinary treatment strategy.	Adults	Strong	Very low to low	NICE_Ad: Page 13; 3.1
		Discuss with the person with cerebral palsy (and their family and carers, if agreed) the balance between the benefits and harms of treating spasticity and dystonia . In particular, explain that some people use their spasticity or dystonia to help their posture and ability to stand, walk or transfer, and that treatment may affect this	Adults	Strong	Very low to low	NICE_Ad: Page 13; 3.2
		If botulinum toxin type A[5] is a proposed treatment option, take into account and explain to the adult with cerebral palsy (and their family and carers, if agreed): that the severity and pattern of dystonia may change after treatment and the potential impact of treatment on function.	Adults	Strong	Very low to low	NICE_Ad: Page 19; 3.23
		Only consider continuous pump-administered intrathecal baclofen[6] if people with cerebral palsy still have difficulties with dystonia, despite having enteral anti-dystonic drug treatment or botulinum toxin type A[5] treatment. Provide information and discuss the procedure, including intrathecal baclofen testing , with the person (and their family or carer, if agreed) as described in recommendations	Adults still have difficulties with dystonia, despite having enteral anti-dystonic drug treatment or botulinum toxin type A[5] treatment.	Conditional	Very low to low	NICE_Ad: Page 19; 3.24
MUSCLE STIFFNESS						
N30	Stretching	Prolonged stretching is an adjunctive intervention to BoNT-A to assist in management of muscle length (level U).*	Children (<18) with cerebral palsy having spasticity in the lower limbs	U	Class IV (Expert opinion)	LOVE: Page 21; Re. 5;
N31	Orthosis	After treatment with botulinum toxin type A, consider an orthosis to: enhance stretching of the temporarily weakened muscle and enable the child or young person to practice functional skills.	Children and young people with spasticity under 19s	Conditional	Low to Moderate	NICE_19: Page 168; Rec. 78

N32	Serial casting	If an orthosis is indicated after botulinum toxin type A, but limited passive range of movement would make this difficult, consider first using serial casting to stretch the muscle . To improve the child or young person's ability to tolerate the cast, and to improve muscle stretching, delay casting until 2–4 weeks after the botulinum toxin type A treatment.	Children and young people with spasticity under 19s	Conditional	Low to Moderate	NICE_19: Page 168; Rec. 79
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MOVEMENT FUNCTIONS						
N33	Assessment	Document the GMFCS and baseline function including, but not limited to, functional gross motor assessment; care needs; what the infant/child can/cannot do; analysis of movement ; gait analysis; functional task analysis; and seating/sleeping positions.	Children (<18) with cerebral palsy having spasticity in the lower limbs	Weak	Class IV (Expert opinion)	LOVE: Page 11; Rec. 1;
		When considering botulinum toxin type A treatment, perform a careful assessment of muscle tone, range of movement and motor function to inform the decision as to whether the treatment is appropriate; provide a baseline against which the response to treatment can be measured. A physiotherapist or an occupational therapist should be involved in the assessment.	Children and young people with spasticity under 19s	Strong	Low to Moderate	NICE_19: Page 168; Rec. 71
		Perform an assessment of muscle tone, range of movement and motor function : 6–12 weeks after injections to assess the response; 12–26 weeks after injections to inform decisions about further injections. These assessments should preferably be performed by the same healthcare professionals who undertook the baseline assessment.	Children and young people with spasticity under 19s	Strong	Low to Moderate	NICE_19: Page 168; Rec.81
CONTROL OF VOLUNTARY MOVEMENT FUNCTIONS						
N34	Positioning	Rehabilitation strategies used by physiotherapists, occupational therapists and speech pathologists are generally considered cornerstones in the management of dystonia in CP. General principles include: 1) ensuring therapy is goal-directed, 2) avoiding asymmetry and aiming for symmetrical positioning to enhance motor control , 3) optimizing seating and positioning with good stability/support, 4) considering orthoses and splints to increase stability and coordination, and 5) considering the need for communication supports.	Individuals at all ages with dystonia in CP	Level U	Expert opinion	DYST: page 1
N35	Orthoses and splints	Rehabilitation strategies used by physiotherapists, occupational therapists and speech pathologists are generally considered cornerstones in the management of dystonia in CP. General principles include: 1) ensuring therapy is goal-directed, 2) avoiding asymmetry and aiming for symmetrical positioning to enhance motor control, 3) optimizing seating and positioning with good stability/support, 4) considering orthoses and splints to increase stability and coordination, and 5) considering the need for communication supports.	Individuals at all ages with dystonia in CP	Level U	Expert opinion	DYST: page 1
GAIT PATTERN AND WALKING						
N36	Assessment	Document the GMFCS and baseline function including, but not limited to, functional gross motor assessment; care needs; what the infant/child can/cannot do; analysis of movement; gait analysis ; functional task analysis; and seating/sleeping positions*	Children (<18) with cerebral palsy having spasticity in the lower limbs	Weak	Class IV (Expert opinion)	LOVE: Page 11; Rec. 1;
		In ambulant children, describe gait and function using scales such as the Physician Rating Scale (PRS) or Observational Gait Scale (OGS) ± video recording*	Children (<18) with cerebral palsy having spasticity in the lower limbs	Weak	Class IV (Expert opinion)	LOVE: Page 11; Rec. 1;
		Instrumented gait analysis is the most objective measure of gait and function in children with CP but its use is largely limited to the research context*	Children (<18) with cerebral palsy ha-	Weak	Class IV (Expert	LOVE: Page 14;

			ving spasticity in the lower limbs		opinion)	Rec. 2;
		Video Gait Analysis may be used both in research and clinical management*	Children (<18) with cerebral palsy having spasticity in the lower limbs	Weak	Class IV (Expert opinion)	LOVE: Page 14; Rec.2;
		Observational gait analysis and the use of gait classifications and observational gait scales are recommended for routine clinical use*	Children (<18) with cerebral palsy having spasticity in the lower limbs	Weak	Class IV (Expert opinion)	LOVE: Page 14; Rec. 2;
N37	Orthoses	For children and young people with equinus deformities that impair their gait consider a solid ankle-foot orthosis if they have poor control of knee or hip extension, a hinged ankle-foot orthosis if they have good control of knee or hip extension.	Children and young people under 19s with equinus deformities that impair their gait	Conditional	Low	NICE_19: Page 109; Rec. 48
		Consider ground reaction force ankle-foot orthoses to assist with walking if the child or young person has a crouch gait and good passive range of movement at the hip and knee.	Children or young person under 19s has a crouch gait and good passive range of movement at the hip and knee.	Conditional	Low	NICE_19: Page 109; Rec. 49
		Consider orthoses for children and young people with spasticity based on their individual needs and aimed at specific goals, such as: improving posture; improving upper limb function; improving walking efficiency ; preventing or slowing development of contractures; preventing or slowing hip migration; relieving discomfort or pain; preventing or treating tissue injury, for example by relieving pressure points.	Children and young people with spasticity under 19s	Conditional	Low	NICE_19: Page 108; Rec.37
		AFOs are an effective adjunctive intervention to improve gait and protect foot integrity (level U).*	Children (<18) with cerebral palsy having spasticity in the lower limbs	U	Class IV (Expert opinion)	LOVE: Page 21; Rec. 5;
		Be aware that in children and young people with secondary complications of spasticity, for example contractures and abnormal torsion, ankle-foot orthoses may not be beneficial .	In children and young people under 19s with secondary complications of spasticity (contractures and abnormal torsion)	Strong against	Low	NICE_19: Page 109; Rec. 47
TRANSFERRING ONESELF						
N38	Orthoses	Consider ankle-foot orthoses for children and young people with serious functional limitations (GMFCS level IV or V) to improve foot position for sitting, transfers between sitting and standing , and assisted standing.	Children and young people under 19s with serious functional limitations	Conditional	Low	NICE_19: Page 109; Rec. 46

			(GMFCS level IV or V)			
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MAINTAINING BODY POSITIONS						
N39	Positioning	Rehabilitation strategies used by physiotherapists, occupational therapists and speech pathologists are generally considered cornerstones in the management of dystonia in CP. General principles include: 1) ensuring therapy is goal-directed, 2) avoiding asymmetry and aiming for symmetrical positioning to enhance motor control, 3) optimizing seating and positioning with good stability/support , 4) considering orthoses and splints to increase stability and coordination, and 5) considering the need for communication supports.	Individuals at all ages with dystonia in CP	Level U	Expert opinion	DYST: page 1
N40	Orthoses	Consider orthoses for children and young people with spasticity based on their individual needs and aimed at specific goals, such as: improving posture ; improving upper limb function; improving walking efficiency; preventing or slowing development of contractures; preventing or slowing hip migration; relieving discomfort or pain; preventing or treating tissue injury, for example by relieving pressure points.	Children and young people with spasticity under 19s	Conditional	Low	NICE_19: Page 108; Rec. 37
		Consider the overnight use of orthoses to: improve posture ; prevent or delay hip migration; prevent or delay contractures.	Children and young people with spasticity under 19s	Conditional	Low	NICE_19: Page 109; Rec. 51
		Consider ankle-foot orthoses for children and young people with serious functional limitations (GMFCS level IV or V) to improve foot position for sitting, transfers between sitting and standing, and assisted standing .	Children and young people under 19s with serious functional limitations (GMFCS level IV / V)	Conditional	Low	NICE_19: Page 109; Rec. 46
		Consider ankle-foot orthoses for children and young people with serious functional limitations (GMFCS level IV or V) to improve foot position for sitting , transfers between sitting and standing, and assisted standing.	Children and young people under 19s with serious functional limitations (GMFCS level IV or V)	Conditional	Low	NICE_19: Page 109; Rec. 46
		Consider body trunk orthoses for children and young people with co-existing scoliosis or kyphosis if this will help with sitting .	Children and young people under 19s with co-existing scoliosis or kyphosis	Conditional	Low	NICE_19: Page 109; Rec. 50
FINE HAND USE						
N41	Orthoses	Consider the following orthoses for children and young people with upper limb spasticity: elbow gaiters to maintain extension and improve function; rigid wrist orthoses to prevent contractures and limit wrist and hand flexion deformity; dynamic orthoses to improve hand function (for example, a non-rigid thumb abduction splint allowing some movement for a child or young person with a 'thumb in palm' deformity).	Children and young people with spasticity under 19s	Conditional	Low	NICE_19: Page 109; Rec. 45

HAND AND ARM USE						
N42	Constraint induced movement therapy	Consider task-focused active-use therapy such as constraint-induced movement therapy (temporary restraint of an unaffected arm to encourage use of the other arm) followed by bimanual therapy (unrestrained use of both arms) to enhance manual skills .	Children and young people with spasticity under 19s	Conditional	Moderate to High	NICE_19: Page 76; Rec. 30

Cochrane Systematic Review: Hoare B et al. 2019; Constraint-induced movement therapy in children with unilateral cerebral palsy.

N of included studies (total participants): 36 (1264)

Population: Children with unilateral cerebral palsy

Setting: Mixed (home, clinic, laboratory, pre-school)

Note: Studies were grouped according to the different outcome measures that have been used.

Intervention	Control	Outcome	No of studies	No of participants	Corresponding risk (95% CI)	Quality of evidence (GRADE)	Statistical method	Heterogeneity
Constraint induced movement therapy	Low-dose comparison	Manual ability	3	95	0.52 [-0.41 to 1.46]	Very low	Mean Difference (IV, Random, 95% CI)	I ² =74% (P = 0.02);
		Individualised measures of performance	3	126	-0.02 [-0.72 to 0.69]	Low		I ² =13% (P = 0.32);
		Individualised measures of performance	6	191	0.08 [-1.29 to 1.46]	Very low		I ² =89% (P<0.00001);
		Self-care	1	34	1.52 [-3.1 to 6.14]	Very low	NR	NA
		Self-care	2	45	-1.09 [-2.42 to 0.24]	Low	Mean Difference (IV, Random, 95% CI)	I ² =8% (P = 0.30);
		Bimanual performance	2	39	5.44 [2.37 to 8.51]	Low		I ² =0.0% P = 0.77
		Bimanual performance	2	60	3.70 [-1.27 to 8.67]	Very low		NR
		Unimanual capacity	1	23	1.98 [-1.55 to 5.51]	Very low		NA
		Unimanual capacity	2	103	6.50 [2.03 to 10.97]	Very low		I ² =66% (P = 0.09);
		Unimanual capacity	1	34	-0.2 [-11.84 to 11.44]	Very low		NA
		Unimanual capacity	1	60	3.70 [-1.91 to 8.71]	Very low		NA
		Unimanual capacity	3	124	6.63 [-2.38 to 15.65]	Very low		I ² =84% (P = 0.002);
		Unimanual capacity	6	203	1.48 [-0.49 to 3.44]	Low		I ² =33% (P = 0.19);
		Bimanual performance	3	126	-0.39 [-3.14 to 2.36]	Low		I ² =31% (P = 0.24);
		Unimanual capacity	1	43	-2 [-5.36 to 1.36]	Very low		NA
	Different forms CIMT	Bimanual performance	2	60	2.19 [-1.15 to 5.53]	Very low		NR
	Dose-matched comparison	Bimanual performance	7	229	0.8 [-0.78 to 2.38]	Low		I ² =21% P = 0.27

N43	Bimanual therapy	Consider task-focused active-use therapy such as constraint-induced movement therapy (temporary restraint of an unaffected arm to encourage use of the other arm) followed by bimanual therapy (unrestrained use of both arms) to enhance manual skills .	Children and young people with spasticity under 19s	Conditional	Moderate to High	NICE_19: Page 76; Rec. 30
		When undertaking task-focused active-use therapy consider an intensive programme over a short time period (for example, 4–8 weeks).	Children and young people with spasticity under 19s	Conditional	Moderate to High	NICE_19: Page 76; Rec. 31
N44	Orthoses	Consider orthoses for children and young people with spasticity based on their individual needs and aimed at specific goals, such as: improving posture; improving upper limb function ; improving walking efficiency; preventing or slowing development of contractures; preventing or slowing hip migration; relieving discomfort or pain; preventing or treating tissue injury, for example by relieving pressure points.	Children and young people with spasticity under 19s	Conditional	Low	NICE_19: Page 108; Rec. 37
USE OF ORTHOSES						
N45	Assessment	Ensure that orthoses are appropriately designed for the individual child or young person and are sized and fitted correctly. If necessary seek expert advice from an orthotist within the network team.	Children and young people with spasticity under 19s	Strong	Low	NICE_19: Page 108; Rec. 40
N46	Monitoring	Be aware when considering a rigid orthosis that it may cause discomfort or pressure injuries in a child or young person with marked dyskinesia. They should be monitored closely to ensure that the orthosis is not causing such difficulties.	Children or young person under 19s with marked dyskinesia	Strong	Low	NICE_19: Page 108; Rec. 41
		If an orthosis is used overnight, check that it is acceptable to the child or young person and does not cause injury; does not disturb sleep.	Children and young people with spasticity under 19s	Strong	Low	NICE_19: Page 108; Rec. 53
		The network team should review the use of orthoses at every contact with the child or young person. Ensure that the orthosis: is still acceptable to the child or young person and their parents or carers remains appropriate to treatment goals is being used as advised remains well fitting and in good repair is not causing adverse effects such as discomfort, pain, sleep disturbance, injury or excessive muscle wasting.	Children and young people with spasticity under 19s	Strong	Low	NICE_19: Page 110; Rec. 54
N47	Education and counselling	When considering an orthosis , discuss with the child or young person and their parents or carers the balance of possible benefits against risks. For example, discuss its cosmetic appearance, the possibility of discomfort or pressure sores or of muscle wasting through lack of muscle use.	Children and young people with spasticity under 19s	Strong	Low	NICE_19: Page 108; Rec. 38
		Inform children and young people who are about to start using an orthosis , and their parents or carers: how to apply and wear it; when to wear it and for how long an orthosis designed to maintain stretch to prevent contractures is more likely to be effective if worn for longer periods of time, for example at least 6 hours a day; an orthosis designed to support a specific function should be worn only when needed when and where to seek advice.	Children and young people with spasticity under 19s	Strong	Low	NICE_19: Page 108; Rec. 43

		Advise children and young people and their parents or carers that they may remove an orthosis if it is causing pain that is not relieved despite their repositioning the limb in the orthosis or adjusting the strapping.	Children and young people with spasticity under 19s	Strong	Low	NICE_19: Page 108; Rec. 44
PREVENTION OF OSTEOPOROSIS						
N48	Assessment	Vitamin D is important for healthy bones and can be low in individuals who have poor nutritional intake or decreased exposure to sunlight. Supplement with regular VitD2/3 (800-1000 international units per day) if the individual lives in a northern climate or has decreased sun exposure as the non-hydroxylated version is very safe. If possible check 25-OH vitamin D levels at baseline and then repeat after 6 months to ensure that the individual is in the normal range.	Children with cerebral palsy who are non- ambulatory and at risk for or have osteoporosis;	Not specified	Not specified	OSTEO: page 1; 2.
		Review the child's growth charts and assess for decreasing weight velocity and/ or low body mass index and if present provide nutritional counselling. Complete a dietary history to estimate Ca intake and check that intake is in the recommended range for age (700 mg elemental Ca for 1 to 3 years of age, 1000 mg for 4 to 8 years of age, and 1300 mg for 9 to 18 years of age).	Children with cerebral palsy who are non- ambulatory and at risk for or have osteoporosis	Not specified	Not specified	OSTEO: page 1; 1.
		Review the child's growth charts and assess for decreasing weight velocity and/ or low body mass index and if present provide nutritional counselling. Complete a dietary history to estimate Ca intake and check that intake is in the recommended range for age (700 mg elemental Ca for 1 to 3 years of age, 1000 mg for 4 to 8 years of age, and 1300 mg for 9 to 18 years of age).	Children with cerebral palsy who are non- ambulatory and at risk for or have osteoporosis	Not specified	Not specified	OSTEO: page 1; 1.
N49	Diet management	If dietary Ca intake is low, provide dietary counselling to increase Ca through the diet (the dietary route is preferred to avoid constipation caused by supplemental Ca).	Children with cerebral palsy who are non- ambulatory and at risk for or have osteoporosis; Children/Young people with cerebral palsy who have a fragility fracture	Level C for improved BMD Level U for decreased fracture rates	For improved BMD: YES: 2 class III. NO: Nil. For decreased fracture rate: YES: Nil; NO: Nil.	OSTEO: page 1; 1.
		Vitamin D is important for healthy bones and can be low in individuals who have poor nutritional intake or decreased exposure to sunlight. Supplement with regular VitD2/3 (800-1000 international units per day) if the individual lives in a northern climate or has decreased sun exposure as the non-hydroxylated version is very safe. If possible check 25-OH vitamin D levels at baseline and then repeat after 6 months to ensure that the individual is in the normal range.	Children with cerebral palsy who are non- ambulatory and at risk for or have osteoporosis; Children/Young people with cerebral palsy who have a fragility fracture	Level C for improved BMD Level U for decreased fracture rates	For improved BMD: YES: 2 class III. NO: Nil. For decreased fracture rate: YES: Nil; NO: Nil.	OSTEO: page 1; 2.

N50	Weight bearing programs	Bearing weight increases bone mineral density. Organize a physiotherapy consult to develop a weight bearing program (e.g. use of a standing frame) .	Children with cerebral palsy who are non-ambulatory and at risk for or have osteoporosis	Level U for improved BMD and decreased fracture rates	For improved BMD: YES: 3 class I, 1 class II, 1 class III NO: 4 class I, 2 class II. For decreased fracture rate: YES: Nil; NO: Nil	OSTEO: page 1; 3.
		Do not offer standing frames solely to prevent low bone mineral density in children and young people with cerebral palsy.	Children and young people under 25:	Strong against	Very low to moderate	NICE_25: Page 285; 19.7. Rec. 82
N51	Vibration therapy	Do not offer vibration therapy solely to prevent low bone mineral density in children and young people with cerebral palsy.	Children and young people under 25:	Strong against	Very low to moderate	NICE_25: Page 285; 19.7. Rec. 83
PREVENTION OF FRACTURES						
N52	Assessment	Consider assessing for risk of fractures secondary to osteoporosis in adults with cerebral palsy. Risk factors to assess include: needing help with moving or having to be moved, for example, hoisting history of falls; low BMI; history of low-impact fractures; other medical factors, for example steroid use, that may adversely affect bone health.	Adults	Conditional	Very low	NICE_Ad: Page 20; 4.3
N53	Assessment: DEXA	Consider a DEXA scan under specialist guidance for children and young people with cerebral palsy who have had a low-impact fracture.	Children and young people under 25: who have had a low-impact fracture.	Conditional	Very low to moderate	NICE_25: Page 285; 19.7. Rec. 80
		Consider a dual-energy X-ray absorptiometry (DXA) assessment in adults with cerebral palsy who have 2 or more risk factors (see recommendation 1.4.3), particularly if they have had a previous low-impact fracture.	Adults with cerebral palsy; adults with cerebral palsy who have 2 or more risk factors (see recommendation 1.4.3), particularly if they have had a previous low-impact fracture.	Conditional	Very low	NICE_Ad: Page 21; 4.4
N54	Assessment Dietary in-	If a child and young person with cerebral palsy has 1 or more risk factors for low bone	Children and young	Conditional	Very low to	NICE_25:

	take	mineral density; assess their dietary intake of calcium and vitamin D and ; consider the following laboratory investigations of calcium and vitamin D status: serum calcium, phosphate and alkaline phosphatase, serum vitamin D, urinary calcium/creatinine ratio.	people under 25: with 1 or more risk factors for low bone mineral density		moderate	Page 285; 19.7. Rec. 77
N55	Mobility training	Consider the following as possible interventions to reduce the risk of reduced bone mineral density and low-impact fractures: an active movement programme ; active weight bearing; dietetic interventions as appropriate, including nutritional support and calcium and vitamin D supplementation; minimising risks associated with movement and handling.	Children and young people under 25:	Conditional	Very low to moderate	NICE_25: Page 285; 19.7. Rec. 79
		Consider the following as possible interventions to reduce the risk of reduced bone mineral density and low-impact fractures: an active movement programme; active weight bearing ; dietetic interventions as appropriate, including nutritional support and calcium and vitamin D supplementation; minimising risks associated with movement and handling.	Children and young people under 25:	Conditional	Very low to moderate	NICE_25: Page 285; 19.7. Rec. 79
		Consider the following as possible interventions to reduce the risk of reduced bone mineral density and low-impact fractures: an active movement programme; active weight bearing; dietetic interventions as appropriate, including nutritional support and calcium and vitamin D supplementation; minimising risks associated with movement and handling .	Children and young people under 25:	Conditional	Very low to moderate	NICE_25: Page 285; 19.7. Rec. 79
N56	Diet management	Consider the following as possible interventions to reduce the risk of reduced bone mineral density and low-impact fractures: an active movement programme; active weight bearing; dietetic interventions as appropriate, including nutritional support and calcium and vitamin D supplementation ; minimising risks associated with movement and handling.	Children and young people under 25:	Conditional	Very low to moderate	NICE_25: Page 285; 19.7. Rec. 79
N57	Education and counselling	Inform children and young people with cerebral palsy and their parents or carers if they are at an increased risk of low-impact fractures.	Children and young people under 25:	Strong	Low to high	NICE_25: Page 285; 18.6. Rec. 76
TREATMENT OF FRACTURES						
N58	Assessment	If an individual with CP has a fragility fracture order additional investigations. These can include bloodwork (Ca, Phosphate, Parathyroid Hormone) , an X-ray of the fracture site, and a DXA scan to determine bone mineral density. Ensure adequate nutrition, Ca and Vit D status. Consult with a pediatric orthopedist for fracture management.	Children/Young people with cerebral palsy who have a fragility fracture	Not specified	Not specified	OSTEO: page 1
		If an individual with CP has a fragility fracture order additional investigations. These can include bloodwork (Ca, Phosphate, Parathyroid Hormone), an X-ray of the fracture site , and a DXA scan to determine bone mineral density. Ensure adequate nutrition, Ca and Vit D status. Consult with a pediatric orthopedist for fracture management.	Children/Young people with cerebral palsy who have a fragility fracture	Not specified	Not specified	OSTEO: page 1
		If an individual with CP has a fragility fracture order additional investigations. These can include bloodwork (Ca, Phosphate, Parathyroid Hormone), an X-ray of the fracture site, and a DXA scan to determine bone mineral density. Ensure adequate nutrition, Ca and Vit D status. Consult with a pediatric orthopedist for fracture management.	Children/Young people with cerebral palsy who have a fragility fracture	Not specified	Not specified	OSTEO: page 1

N59	Bisphosphonates	Bisphosphonates should also be considered in children although the long-term safety on growing bones is unknown. Bisphosphonates help to build bone density by suppressing bone resorption. Consultation with a bone specialist (endocrinologist, orthopedist, physician with special interest in bone health) is recommended. In children, bisphosphonates are typically given intravenously three to four times per year rather than orally.	Children/Young people with cerebral palsy who have a fragility fracture	Level B for improved BMD Level C for decreased fracture rates	For improved BMD: YES: 2 class I; 6 class III NO: 1 class I. For decreased fracture rate: YES: 1 class II; 2 class III NO: 2 class III	OSTEO: page 1
N60	Diet management	If an individual with CP has a fragility fracture order additional investigations. These can include bloodwork (Ca, Phosphate, Parathyroid Hormone), an X-ray of the fracture site, and a DXA scan to determine bone mineral density. Ensure adequate nutrition, Ca and Vit D status . Consult with a pediatric orthopedist for fracture management.	Children/Young people with cerebral palsy who have a fragility fracture	Not specified	Level C for improved BMD Level U for decreased fracture rates	OSTEO: page 1
		If an individual with CP has a fragility fracture order additional investigations. These can include bloodwork (Ca, Phosphate, Parathyroid Hormone), an X-ray of the fracture site, and a DXA scan to determine bone mineral density. Ensure adequate nutrition, Ca and Vit D status . Consult with a pediatric orthopedist for fracture management.	Children/Young people with cerebral palsy who have a fragility fracture	Not specified	Level C for improved BMD Level U for decreased fracture rates	OSTEO: page 1

NOTES:

O) Interventions for Activities of daily living

N°	Intervention	Original recommendation	Specification of target population	SoR	QoE	Ref.
SELF-CARE						
O1	Assessment	Before performing the intrathecal baclofen test, assess the following where relevant to the treatment goals: spasticity; dystonia; the presence of pain or muscle spasms; postural difficulties, including head control; functional difficulties; difficulties with self-care (or ease of care by parents or carers). If necessary, assess passive range of movement under general anaesthesia.	Children and young people with spasticity under 19s	Strong	Very low to Moderate	NICE_19: Page 205; Rec. 92
		Assess the care needs of every child with cerebral palsy, and of their parents or carers, at diagnosis, and reassess regularly.	Children and young people under 25:	Strong	Low to moderate	NICE_25: Page 408; 28.7. Rec. 145
		Assess whether an orthosis might: cause difficulties with self-care or care by others cause difficulties in relation to hygiene be unacceptable to the child or young person because of its appearance.	Children and young people with spasticity under 19s	Strong	Low	NICE_19: Page 108; Rec. 39
EATING						
O2	Assessment	If eating , drinking and swallowing difficulties are suspected in a child or young person with cerebral palsy, carry out a clinical assessment as first-line investigation to determine the safety, efficiency and enjoyment of eating and drinking. This should include: taking a relevant clinical history, including asking about any previous chest infections, observation of eating and drinking in a normal mealtime environment by a speech and language therapist with training in assessing and treating dysphagia.	Children and young people under 25:If eating, drinking and swallowing difficulties are suspected	Strong	Very low to low	NICE_25: Page 189; 12.6. Rec. 43
		Use outcome measures important to the child or young person and their parents or carers to review: whether individualised goals have been achieved ; the clinical and functional impact of interventions to improve eating , drinking and swallowing.	Children and young people under 25	Strong	Very low to low	NICE_25: Page 212; 13.7. Rec. 53
		At every review, discuss with adults with cerebral palsy (and their family and Cerebral palsy in adults carers, if agreed) whether they have difficulties with eating or if there have been any changes in their eating habits or bowel function. Ask about issues including: changes in appetite; changes in the person's ability to feed themselves; constipation; coughing or choking when eating; food refusal; increased frequency of chest infections (which may be related to swallowing; difficulties or gastro-oesophageal reflux); an increase in the length of meal times.	Adults	Strong	Expert opinion	NICE_Ad: Page 23; 4.17
		Develop strategies and goals in partnership with the child or young person with cerebral palsy and their parents, carers and other family members for interventions to improve eating , drinking and swallowing	Children and young people under 25	Strong	Very low to low	NICE_25: Page 211; 13.7 Rec. 50

O3	Education and counseling	Advise parents or carers that intra-oral devices have not been shown to improve eating , drinking and swallowing in children and young people with cerebral palsy.	Children and young people under 25	Strong	Very low to low	NICE_25: Page 211; 13.7. Rec. 52
		Develop strategies and goals in partnership with the child or young person with cerebral palsy and their parents, carers and other family members for interventions to improve eating , drinking and swallowing.	Children and young people under 25	Strong	Very low to low	NICE_25: Page 211; 13.7. Rec. 50
DRINKING						
O4	Assessment	If eating, drinking and swallowing difficulties are suspected in a child or young person with cerebral palsy, carry out a clinical assessment as first-line investigation to determine the safety, efficiency and enjoyment of eating and drinking . This should include: taking a relevant clinical history, including asking about any previous chest infections, observation of eating and drinking in a normal mealtime environment by a speech and language therapist with training in assessing and treating dysphagia.	Children and young people under 25:If eating, drinking and swallowing difficulties are suspected	Strong	Very low to low	NICE_25: Page 189; 12.6 Rec. 43
		Use outcome measures important to the child or young person and their parents or carers to review: whether individualised goals have been achieved ; the clinical and functional impact of interventions to improve eating, drinking and swallowing.	Children and young people under 25	Strong	Very low to low	NICE_25: Page 211; 13.7. Rec. 53
O5	Education and counseling	Develop strategies and goals in partnership with the child or young person with cerebral palsy and their parents, carers and other family members for interventions to improve eating, drinking and swallowing.	Children and young people under 25	Strong	Very low to low	NICE_25: Page 211; 13.7. Rec. 51
		Advise parents or carers that intra-oral devices have not been shown to improve eating, drinking and swallowing in children and young people with cerebral palsy.	Children and young people under 25	Strong	Very low to low	NICE_25: Page 211; 13.7. Rec. 52

NOTES:

P) Rehabilitation interventions for exercise and fitness

N°	Intervention	Original recommendation	Specification of target population	SoR	QoE	Ref.
EXERCISE TOLERANCE FUNCTIONS						
P1	Education and counseling	Discuss with adults with cerebral palsy (and their families or carers, if agreed) the importance of physical activity in maintaining general fitness and physical and mental health	Adults	Strong	Very low to low	NICE_Ad: Page 13; 2.18
		Provide information on accessible local services that support people with cerebral palsy to take part in physical activity.	Adults	Strong	Very low to low	NICE_Ad: Page 13; 2.19

Cochrane Systematic Review: Ryan JM et al. 2017; Exercise interventions for cerebral palsy

N of included studies (total participants): 29 (926)

Population: Children and adolescents with cerebral palsy

Setting: Community, outpatients, home patients

Note: Studies were grouped according to the different outcome measures that have been used.

Intervention	Control	Outcome	No of studies	No of participants	Corresponding risk (95% CI)	Quality of evidence (GRADE)	Statistical method	Heterogeneity
Aerobic exercise	Usual care	Activity	3	65	0.53 [0.02 to 1.04]	Low	Std. Mean Difference (IV, Random, 95% CI)	I ² =0.0% (P = 0.86);
		Activity	4	82	0.09 [-0.11 to 0.28]	Very low		I ² =78% (P = 0.004);
		Activity	3	85	0.13 [-0.30 to 0.55]	Low		I ² =0.0% (P = 0.62);
		Activity	8	185	0.03 [-0.02 to 0.07]	Low		I ² =0.0% (P = 0.65);
		Activity	3	84	-0.03 [-0.17 to 0.11]	Low		I ² =0.0% (P = 0.73);
		Participation	2	127	0.34 [-0.01 to 0.70]	Low		I ² =0.0% (P = 0.41);
Mixed training	Usual care	Activity	4	163	0.02 [-0.29 to 0.33]	Low		I ² =1% (P = 0.37);
Resistance training	Usual care	Activity	7	164	0.12 [-0.19 to 0.43]	Low		I ² =0.0% (P = 0.62);
	Aerobic exercise	Activity	2	56	0.02 [-0.50 to 0.55]	Low		I ² =0.0% (P = 0.66);

NOTES:

R) Interventions for Interactions and relationships

N°	Intervention	Original recommendation	Specification of target population	SoR	QoE	Ref.
INTERPERSONAL INTERACTIONS AND RELATIONSHIPS						
R1	Assessment	At every review, explore with the adult with cerebral palsy (and their family and carers, if agreed) if they have any concerns about, for example, their mood; irritability; behaviour; social interaction sleep; general level of function.	Adults	Strong	Expert opinion	NICE_Ad: Page 22; 4.12
R2	Education and counseling	Talk to children and young people and their parents or carers about behavioural difficulties that can be associated with cerebral palsy. Information that may be useful to discuss includes that around 2 to 3 in 10 children and young people with cerebral palsy have 1 or more of the following: emotional and behavioural difficulties that have an effect on the child or young person's function and participation; problems with peer relationships; difficulties with attention, concentration and hyperactivity; conduct behavioural difficulties.	Children and young people under 25	Strong	High	NICE_25: Page 387; 27.20. Rec. 133
PARENTING						
R3	Education and counseling	Ensure that the child or young person and their parents or carers are provided with information , by a professional with appropriate expertise, about the following topics relevant to them that is tailored to their individual needs: parenting .	Children and young people under 25	Strong	Low to moderate	NICE_25: Page 182; 11.6. Rec. 40

NOTES:

S) Rehabilitation interventions for education and vocation

N°	Intervention	Original recommendation	Specification of target population	SoR	QoE	Ref.
WORK AND EMPLOYMENT						
S1	Education and counseling	Refer adults with cerebral palsy who would like to work, or who are already working, to a professional with expertise in vocational skills and independent living (for example, an occupational therapist). Give information and advice, which could include: continued education; job seeking or access to work schemes; employment support to include workplace training and job retention occupational health assessment or workplace assessment; statutory welfare benefits supporting a planned exit from the workforce if it becomes too difficult to continue working; vocational rehabilitation; voluntary work.	Adults	Strong	Low	NICE_Ad: Page 11; 2.12

NOTES:

T) Interventions for Community and social life

N°	Intervention	Original recommendation	Specification of target population	SoR	QoE	Ref.
COMMUNITY AND SOCIAL LIFE						
T1	Assessment	Ask adults with cerebral palsy what they enjoy doing and if they find it difficult to participate in a chosen activity , assess their physical and mental health, and address any factors identified that may be affecting participation, if possible.	Adults	Strong	Expert opinion	NICE_Ad: Page 11; 2.8
T2	Use of electronic assistive devices	If adults with cerebral palsy are already using electronic assistive technology, discuss at every review any: problems or concerns they have with their equipment; potential changes in their needs .	Adults	Strong	Expert opinion	NICE_Ad: Page 12; 2.16
		Discuss with adults with cerebral palsy the potential role of electronic assistive technology if they have problems with participation and independence .	Adults	Strong	Expert opinion	NICE_Ad: Page 12; 2.13
		If adults with cerebral palsy have complex physical, cognitive, language or sensory needs, consider referring them to services providing information, assessment and provision of electronic assistive technology .	Adults with complex physical, cognitive, language or sensory needs	Conditional	Expert opinion	NICE_Ad: Page 12; 2.14
		Ensure that training is provided for adults with cerebral palsy using electronic assistive technology, and for their families or carers , if appropriate.	Adults	Strong	Expert opinion	NICE_Ad: Page 13; 2.17
RECREATION ND LEISURE						
T3	Education and counseling	Refer adults with cerebral palsy who would like to live independently to a professional with expertise in independent living (for example, an occupational therapist). Give information and advice, which could include: adaptations to their home; housing; leisure activities ; statutory welfare benefits.	Adults	Strong	Expert opinion	NICE_Ad: Page 11; 2.11
PHYSICAL ENVIRONMENT						
T4	Assessment	Address and review the specific needs of the child or young person with cerebral palsy in relation to accessing their physical environment (for example, home, school, healthcare, workplace, community), in order to optimise their functional participation. Think about the following aspects: mobility; equipment, particularly wheelchairs and hoists; transport; toileting and changing facilities.	Children and young people under 25	Strong	Low to moderate	NICE_25: Page 409; 28.7. Rec. 148
		Identify and address any factors that prevent people with cerebral palsy from participating in activities, including: physical barriers , for example, access to buildings; personal barriers, for example, carers with unmet training needs; organisational barriers, for example, policies and situations that put people with cerebral palsy at a disadvantage.	Adults	Strong	Expert opinion	NICE_Ad: Page 10; 2.7
T5	Environmental modification	Refer adults with cerebral palsy who would like to live independently to a professional with expertise in independent living (for example, an occupational therapist). Give information and advice, which could include: adaptations to their home; housing ; leisure	Adults	Strong	Expert opinion	NICE_Ad: Page 11; 2.11

		activities; statutory welfare benefits.				
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V) Interventions for self-management

N°	Intervention	Original recommendation	Specification of target population	SoR	QoE	Ref.
SUPPORT GROUPS						
V1	Education and counseling	Provide information on the following topics, and direct families to where they can find further information, at diagnosis of cerebral palsy and as appropriate thereafter: social care services; financial support, welfare rights and voluntary organisations; support groups (including psychological and emotional support for the child or young person and their parents or carers and siblings) ; respite and hospice services.	Children and young people under 25	Strong	Low to moderate	NICE_25:
		Provide information about local support and advocacy groups to the child or young person and their parents or carers.	Children and young people under 25	Strong	Low to moderate	NICE_25:
		Provide information about local support to the child or young person and their parents or carers.	Children and young people under 25	Strong	Low to moderate	NICE_25:
SOCIAL CARE SERVICES						
V2	Education and counseling	Provide information on the following topics, and direct families to where they can find further information, at diagnosis of cerebral palsy and as appropriate thereafter: social care services ; financial support, welfare rights and voluntary organisations; support groups (including psychological and emotional support for the child or young person and their parents or carers and siblings); respite and hospice services.	Children and young people under 25	Strong	Low to moderate	NICE_25:
		Provide information on the following topics, and direct families to where they can find further information, at diagnosis of cerebral palsy and as appropriate thereafter: social care services; financial support, welfare rights and voluntary organisations ; support groups (including psychological and emotional support for the child or young person and their parents or carers and siblings); respite and hospice services.	Children and young people under 25	Strong	Low to moderate	NICE_25:
		Provide information on the following topics, and direct families to where they can find further information, at diagnosis of cerebral palsy and as appropriate thereafter: social care services; financial support, welfare rights and voluntary organisations; support groups (including psychological and emotional support for the child or young person and their parents or carers and siblings); respite and hospice services .	Children and young people under 25	Strong	Low to moderate	NICE_25:
		Explore with the child or young person and their parents or carers the value of respite services, such as carer support either at home or in another setting.	Children and young people under 25	Strong	Low to moderate	NICE_25:
		Refer adults with cerebral palsy who would like to live independently to a professional with expertise in independent living (for example, an occupational therapist). Give information and advice, which could include: adaptations to their home; housing; leisure activities; statutory welfare benefits .	Adults	Strong	Expert opinion	NICE_Ad: Page 11; 2.11
SOCIAL SUPPORT SERVICES						
V3	Education and counseling	Provide information to the child or young person and their parents or carers, and to all relevant teams around them, about the local and regional services available (for example, sporting clubs, respite care and specialist schools) for children and young people with cerebral palsy, and how to access them.	Children and young people under 25	Strong	Low to moderate	NICE_25: Page 182; 11.6. Rec. 41

HEALTH SERVICES						
V4	Education and counseling	Ensure that adults with cerebral palsy, their families and carers, and their primary care teams are provided with information about their local network of specialist services.	Adults	Strong	Expert opinion	NICE_Ad: Page 7; Rec. 1.4
		Give information to people with cerebral palsy about national screening services (for example, breast, colon and cervical cancer screening) and encourage them to attend screening appointments. Explain that screening services will have to make arrangements to provide screening services that are accessible to people with cerebral palsy.	Adults		Expert opinion	NICE_Ad: Page 8; Rec. 1.10

NOTES: