

Pain Management in Patients with Complex Needs

Target patient groups: Neurodivergent patients, learning disabilities, long-standing chronic pain.

Version: 1.0
Date Issued: 22/06/2026
Review Date: 01/06/2029
Key words: Complex pain Neurodiversity, Chronic Pain Acute Pain, Intellectual Difficulties Learning Disability Sensory Processing Differences, Non-speaking Complex pain

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Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
CDT	Community Drugs Team
DisDat	Disability Distress Assessment Tool
ED	Emergency department
FHFT	Frimley Health Foundation NHS Trust
FLACC	Face, Legs, Activity, Cry, Consolability -FLACC Pain Scale
FPH	Frimley Park Hospital
HWD	Heatherwood Hospital
ID	Intellectual disability
LD	Learning Disability
ND	Neurodivergent
NSAID	Non-steroidal anti-inflammatory drugs
PAINAD	Pain Assessment in Advanced Dementia
SL	Sub lingual
WPH	Wexham Park Hospital

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Aim

To provide FHFT clinicians with guidance on supporting these patient groups by using effective communication methods, optimising the care environment and engaging in multidisciplinary training to enhance patient experience.

Introduction

Effective pain management relies on the interaction of multiple systems — physical, neurological, emotional, and psychological. A multimodal approach recognises this complexity and emphasises clear, personalised communication, a supportive and sensory aware environment, and coordinated input from the wider multidisciplinary team. This guideline aims to support clinicians in delivering care that is both evidence-based and responsive to individual patient needs. By integrating clinical assessment with an understanding of each patient's cognitive, behavioural, and social context, the service promotes safer, more accessible, and true patient centred pain management.

In addition, it is important to recognise that acquired cognitive impairment occurs later due to events such as brain injury, stroke, infection, trauma, or long-term health conditions. Assessment should focus on identifying what is new compared with the individual's established baseline.

A trauma-informed approach should underpin all interactions with patients with complex needs, recognising that these groups experience disproportionately high rates of adverse life experiences and medical trauma; care should prioritise predictability, choice, and collaboration to minimise the risk of re-traumatisation in the clinical environment.

Complex pain

The Faculty of Pain Medicine's 2020 commissioning guidance and 2022 Practical Pain Management document use the term to describe pain conditions that are refractory, multi-mechanistic, or involve significant central sensitisation.

Complex needs

Refers to the patient's circumstances, communication requirements, cognitive profile, or comorbidities that necessitate adapted care delivery. It is a descriptor of the person and the system's response to them. This incorporates input relevant to patients with acquired cognitive impairment, in addition to those with congenital or developmental learning disabilities. This includes individuals affected by dementia (Alzheimer's, vascular, Lewy body, frontotemporal) and those with traumatic brain injury, stroke-related cognitive deficits, post-cardiac arrest or hypoxic brain injury, delirium (acute, often reversible), and cognitive impairment secondary to conditions like multiple sclerosis, Parkinson's, or HIV.

Quick Reference Table

Factors	Key Actions
Communication	Adapt tools, recognise non-verbal cues, Carer and Family Involvement
Assessment	Communication adapted- assessment, use of appropriate pain tools, behavioural and baseline comparison, holistic and multimodal assessment, documentation and consistency
Neurodiversity/LD	Clear explanations, accessible methods, carer input, sensory considerations
Chronic Pain	Address psychological/social impact, holistic management, regular review
Medication management	Monitor interactions, minimise duplication, pharmacist support- medicines reconciliation
Multidisciplinary Care	Team based approach, individualised plans, continuity of care-based approach, individualised plans, continuity of care

Neurodivergence (ND)

Neurodivergence is a term used to describe natural differences in how our brains think, process information, learn and behave. Neurodivergence encompasses the *whole person*, including physical coordination and sensory processing; emotional differences, such as the intensity of emotional experience and the ability to recognise and express emotion; cognitive differences, such as thinking in words or in pictures, and social interaction. It encompasses conditions such as autism, ADHD, Tourette's and Dyslexia.

This table summarises the guidelines provided for pain assessment and management specifically for ND patients.

Category	Key Guidance and Strategies	Supporting Details and Rationale
Individualised Pain Assessment	Use visual aids, such as pain scales or pictorial representations, to assist in pain articulation and localisation.	Recognise that pain perception can vary significantly; some neurodivergent individuals may be relatively insensitive to pain, while others might experience intense pain from unique sources.
Communication & Support	Incorporate supportive individuals (family, friends, or caregivers) in the care plan.	This inclusion helps facilitate communication between the patient and healthcare providers. Be aware of potential communication differences, such as a preference for written communication over verbal.
Sensory Considerations	Minimise unnecessary sensory stimuli by creating a calm and predictable environment.	Consider providing weighted blankets or fidget toys to help meet sensory needs. Be mindful of potential sensory sensitivities to pain medications and be prepared to adjust pain management strategies if necessary.
Pain Management Strategies	Utilise multimodal analgesia—a combination of medications such as paracetamol, NSAIDs, and other options—to manage pain effectively without relying heavily on opioids.	Consider using regional anaesthetic techniques (e.g. nerve blocks) to provide targeted pain relief. Incorporate non-pharmacological approaches, such as deep breathing exercises, relaxation techniques, or guided imagery, to promote relaxation and reduce anxiety.
Preoperative Planning	Engage in shared decision-making with the patient and their support system, discussing options and considering their preferences and concerns.	Screen for potential risk factors for severe acute and chronic pain in the postoperative period, including pre-existing anxiety or depression. Help patients understand the typical pain trajectory and the importance of early mobilisation (Expectation management).
Addressing Potential Challenges	Provide a safe and structured environment to manage hyperactivity (excessive movement or restlessness).	Acknowledge that self-stimulatory behaviours can function as a coping mechanism and provide alternative strategies if needed. Develop strategies to de-escalate situations concerning non-compliance, such as emotional dysregulation or aggression.

Pain management in neurodivergent individuals should prioritise individualised approaches, effective communication, and a supportive environment to address sensory sensitivities and potential challenges. By implementing these strategies, healthcare providers can better address the unique pain experiences and needs of ND individuals in the postoperative period, leading to improved pain management, patient satisfaction, and recovery outcomes.

Learning Disability (LD)

This table summarises the guidelines provided for pain assessment and management specifically for individuals with Learning Disabilities (LD)

Category	Guidelines for Pain Assessment and Management in Individuals with LD
Core Principles	Always consider pain as a cause of behavioural, mood, or functional change. Individuals with LD are at increased risk of unrecognised and undertreated pain. Use a person-centred, trauma-informed, & accessible communication approach. If behaviour remains unexplained, reconsider pain before attributing symptoms to behavioural or psychiatric causes.
Communication & Assessment	Use the person's preferred communication method (simple language, symbols, gestures, communication aids). Allow extra time. Consult with carers/family about baseline behaviours and known pain cues. Reassess pain regularly and after all interventions.
Behavioural Indicators	Look for facial expressions (grimacing, frowning) & vocalisations (moaning, crying, repetitive sounds). Indicators include restlessness, withdrawal, aggression, or self-injury. Note changes in appetite, sleep, mobility, or routine participation.
Validated Assessment Tools	Tools recommended include the DisDAT (Disability Distress Assessment Tool), the FLACC Scale, & PAINAD or Bolton pain assessment tool (if non-speaking and/or dementia or cognitive decline is present).
Non-Pharmacological Management	Strategies include repositioning, mobility support, & physiotherapy. Apply heat/cold packs when appropriate. Use relaxation, distraction, sensory modulation, or music. Reduce environmental stressors such as noise, crowding, or sensory overload.
Pharmacological Management	Use the standard multimodal approach for acute pain following the principle to start low, go slow. Monitor effectiveness & side-effects frequently. Consider potential drug interactions, especially with antiepileptics, psychotropics, or sedatives. Review long-term analgesics routinely, including opioids & NSAIDs.
Documentation & Review	Record baseline behaviours, communication needs, assessment tools/scores, interventions used, response to treatment, & any safeguarding concerns. Document the indication, response, and review plan for all analgesics
Involvement & Escalation	Involve carers/family in assessment, care planning, and monitoring. Ensure staff training in recognising pain behaviours & communication methods. Refer to pain specialists, LD services, psychology, physiotherapy/ OT for complex or persistent pain.
Safeguarding	Unexplained or persistent pain, behavioural change, or injury may indicate abuse or neglect. Follow local safeguarding procedures & document concerns clearly.
Capacity assessment	Capacity should be assessed and documented clearly, ensuring decisions follow the best interests process when a person lacks capacity, and any restrictions on their freedom are the least restrictive and compliant with DoLS requirements. This includes recognising when a deprivation of liberty may be occurring and escalating promptly through local safeguarding and legal pathways.

Patients with long-standing chronic pain

- Patients who have a history of chronic pain may find that it complicates admission to hospital. A careful history should be taken and existing pain management strategies and medications noted. The patient with chronic pain is usually an expert in how best to manage their existing pain. The patient should be supported to continue to manage their chronic pain in their usual way as much as possible in hospital. Additional analgesia should be provided for pain that is new or is additional to their 'normal' chronic pain.
- Patients with chronic pain can sometimes be on very unusual analgesic regimens when they present to acute hospital care. Usual practice would be to continue their usual regimen whilst an inpatient (unless contraindicated or unsafe). Additional immediate release opioids, as part of a multimodal regimen, could be used to manage additional acute pain needs. Any escalation to existing modified release preparations should be avoided or only undertaken after specialist advice from the Inpatient Pain Team/Palliative Care Team or Pharmacy.
- If a patient has an opioid patch and is going for surgery, the patch should be left in place and the anaesthetist informed. Diathermy plates and blood pressure cuffs should not be placed over opioid patches and care should be taken not to artificially heat the patch in any other way as this may increase release of the medication.

Safety netting/After discharge

Primary care usually manages ongoing pain once a patient leaves hospital. Any changes made to analgesia during admission should be clearly communicated to the patient, their carers, and their GP.

Provide a clear plan for how analgesia should be reduced, tapered, or adjusted after discharge, especially when opioids have been used.

Use caution with new or additional opioids prescribed to take home. Evidence shows that each extra week of opioid use increases the risk of misuse by around 20% (Brat et al., 2018).

Avoid issuing repeat opioid prescriptions in primary care. Patients and carers should be advised about:

- The risks of drug driving
- The potential for opioid diversion
- Safe storage of opioids at home
- Safe disposal of unused medication

Provide discharge pain plans in accessible formats (Easy Read, visual aids) for people with learning disabilities.

Clarify the role of carers and support staff in monitoring pain and reporting concerns after discharge.

Ensure GP handover flags complex needs and highlights any adapted analgesia strategies that worked in hospital.

Recognise the risk of medication errors when carers administer complex regimens without formal training.

Consider the needs of neurodivergent patients, for whom changes in routine, new medicines, or altered schedules may increase distress.

Retain opioid stewardship principles, noting they are not specific to learning disability or neurodivergent or chronic pain populations.

Who to contact for help

FHFT Inpatient Pain Service: [Pain Contact details](#)

FHFT Learning Disability Service: [Learning disabilities extranet page](#)

FHFT Pharmacy contacts: [Pharmacist/ Medicines Information Team](#)

References and further reading

- Doody, O. and Bailey, M.E. (2019) 'Interventions in pain management for persons with an intellectual disability', *Journal of Intellectual Disabilities*, 23(1), pp.132-144.
- El-Boghdadly, K., Levy, N.A., Fawcett, W.J., Knaggs, R.D., Laycock, H., Baird, E., Cox, F.J., Eardley, W., Kemp, H., Malpus, Z. and Partridge, A. (2024) 'Peri-operative pain management in adults: a multidisciplinary consensus statement from the Association of Anaesthetists and the British Pain Society. *Anaesthesia*', 79(11), pp.1220-1236.
- El-Tallawy, S.N., Ahmed, R.S. and Nagiub, M.S. (2023). 'Pain management in the most vulnerable intellectual disability: a review. *Pain and therapy*', 12(4), pp.939-961.
- Faculty of Pain Medicine (2020) '*Improving the lives of people with complex chronic pain: how to commission effective pain management*'. Available at: <https://www.fpm.ac.uk/media/2461> (Accessed: 11 February 2026).
- Faculty of Pain Medicine (2022) '*Practical pain management in specialist care: how to help people with chronic pain when population based national guidance fails to help*'. Available at: https://fpm.ac.uk/sites/fpm/files/documents/2022-02/Practical%20Pain%20Management%202022_0.pdf (Accessed: 11 February 2026).
- Ginevra, B. and Hadassah, B. (2025) '220 Provision of healthcare and management of chronic pain in children with neurodivergence'.
- Hutton, T.E. and Aslam, N. (2025) E072 'Autism and chronic pain: the holistic way forward'. *Rheumatology*, 64(Supplement_3), pp. keaf142-307.
- Jenkinson, D.J., Bailey, J., Mughal, F., Dunn, K.M. and Mason, K.J., 'Do Children and Young People with Mental Health Conditions or Neurodiversity Experience Different Management for Musculoskeletal Pain?' An Electronic Primary Health Care Record Study. *An Electronic Primary Health Care Record Study*.
- Moreno-Duarte, I., Brandsen, S., Dawson, G., Einhorn, L.M. and Swaminathan, M. (2024) 'Integrating tailored approaches in perioperative care strategies for neurodivergent individuals'. *EClinicalMedicine*, 76.
- National Institute for Health and Care Excellence [NICE] (2021) *Chronic pain (primary and secondary) in over 16s: assessment of all chronic pain and management of chronic primary pain*. NG193. Available at: <https://www.nice.org.uk/guidance/ng193> (Accessed: 11 February 2026)

Further resources:

[hospital-communication-book-version-3-for-web-2021-high-res.pdf](#)

[This is me | Alzheimer's Society](#)

https://www.alzheimers.org.uk/sites/default/files/2020-03/this_is_me_1553.pdf

[The Oliver McGowan Mandatory Training on Learning Disability and Autism Part 1 eLearning Microsoft Word - DisDAT-19.doc](#)

[LPS Neurodivergence and Pain.pdf](#)

Full version control record

Version:	1
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Library check completed:	16/06/2026
Ratified at:	Anaesthetic Clinical Governance: 21/05/2026 Nursing, Midwifery and Quality Board: 07/05/2026
Date Issued:	22/06/2026
Review Date:	01/06/2029
Pharmaceutical dosing advice and formulary compliance checked by:	N/A
Key words:	Complex pain Neurodiversity, Chronic Pain Acute Pain, Intellectual Difficulties Learning Disability Sensory Processing Differences, Non-speaking Complex pain

This guideline has been registered with the Trust. However, clinical guidelines are guidelines only. The interpretation and application of clinical guidelines will remain the responsibility of the individual clinician. If in doubt, contact a senior colleague or expert. Caution is advised when using guidelines after the review date.

This guideline is for use in Frimley Health NHS Foundation Trust hospitals only. Any use outside this location will not be supported by the Trust and will be at the risk of the individual using it.

Version History

Version	Date	Guideline Lead(s)	Status	Comment
1	June 2026	Liz Murphy & Aleyamma Thomas	Final	New Guideline Ratified at: Anaesthetic Clinical Governance: 21/05/2026 Nursing, Midwifery and Quality Board: 07/05/2026 DTC: N/A

Related Documents

Document Type	Document Name
Policy	Supporting patients with a Learning Disability Policy
Trust Guideline	Optimising Analgesia in Adult Patients with Chronic Pain
Trust Guideline	Optimising Analgesia for Adult In patients with Acute pain